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Global Bioethics:

20th anniversary of UNESCO's
Bioethics Programme

What for?



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20th anniversary of
UNESCO's Bioethics
Programme

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Global Bioethics: What for?

Twentieth anniversary of UNESCO's Bioethics Programme
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Introduction

The General Conference,

1. *Approves* the establishment by the Director-General of UNESCO of the International Bioethics Committee;
2. *Invites* the Director-General to continue in 1994-1995 the preparation of an international instrument on the protection of the human genome and to report to it at its twenty-eighth session on the implementation of this resolution.

In the early 1990s in different parts of the world, the most extraordinary scientific discoveries were made with regard to the human genome, opening up endless prospects for potential intervention during a person's lifetime and even in the design of that life. In the background, rear up the old phantoms of eugenics and the unchaining of Prometheus (Martin, González, Poamé). As Federico Mayor notes in the article he wrote for this book, from the beginning of time humankind has pondered on the conflict between what is feasible and what is admissible, and between the right or wrong use of knowledge, because 'although knowledge is always positive, its application may not be'. With lucid, responsible foresight, the Director-General of UNESCO established the International Bioethics Committee (IBC) to deal precisely with that which may be admissible in the use of knowledge with regard to life, for all humanity.¹

Because of the unease that progress in the life sciences, and genetics in particular, is causing throughout the world, I decided to set up the International Bioethics Committee (IBC), which was inaugurated at UNESCO Headquarters on 15 and 16 September 1993. When all the sciences are now more than ever questioning their own ultimate purposes, it becomes a matter of urgency to ask how ethical enquiry is to go hand in hand with scientific development without, at the same time, impeding freedom of research. It is in this context that UNESCO

1 Based on the resolution adopted by the General Conference at its twenty-first plenary session on 15 November 1993.

*must fulfil its educational role and promote international teaching and scientific cooperation.*²

It can be said that the roots of UNESCO's work on bioethics date back to the 1970s. In 1975, in Varna, Bulgaria, the first meeting was held to reflect on the relation between ethics and (molecular) biology³ and in 1977, a symposium was held in Madrid, Spain, on genetics and ethics, organized respectively by UNESCO's Philosophy Division and the Scientific Research and Higher Education Division.⁴ But it was not until 1985 that an ethical stance began to be adopted within the framework of Human Rights, during the Symposium held in Barcelona on 'Genetic Manipulation and Human Rights', organized by UNESCO's Division of Human Rights and Peace.⁵ In 1991, warning bells began to ring when the United States National Institutes of Health opened a Pandora's box with the issue of privatization and patenting of the genome, immediately following the launch of the international project on the human genome. This was, without doubt, what prompted the Director-General at the time to found the Bioethics Programme at UNESCO, in order to oversee the universal regulation of developments and applications connected with the sequencing of the genome.⁶ The Bioethics Unit was established within the UNESCO Secretariat's Social and Human Sciences Sector and later, in 1977, became the Division of the Ethics of Science and Technology, initially under the directorship of Georges Kutukdjian and later, from 2003 to 2010, directed by Henk ten Have. Since then, a new Bioethics Section has been headed by Dafna Feinholz. From 2014, this same section has changed its name to Bioethics and Ethics of Science.

On 6 September 2013, a symposium was organized to celebrate the twentieth anniversary of UNESCO's Bioethics Programme: 'The role of UNESCO in Bioethics over the next twenty years'. Among the participants were seven of the contributors to this book (Nouzha Guessous, Henk ten Have, Georges Kutukdjian, Stefano Semplici, Michèle Stanton-Jean, Aissatou Touré and Yongyuth Yuthavong).

Following the symposium, the Secretariat made a widespread appeal to its principal interlocutors: past and present members of

2 Federico Mayor, Preface of Proceedings 1994 of the IBC of UNESCO. <http://unesdoc.unesco.org/images/0012/001203/120377mo.pdf>

3 See B. Ribes, 1978, *Biology and Ethics*, Paris, UNESCO, p. 189.

4 Symposium on Genetics and Ethics: Problems and Positive Results of Scientific Research in Genetics Final Report (English only) 1978 SC-77/conf.805/col16, 10p. Study on the current need for international cooperation in the field of basic biological sciences.

5 International Symposium on the effect on Human Rights of recent advances in science and technology. Conclusions and Recommendations, UNESCO, SHS-86/WS/39, 1985.

6 See particularly the article by Georges Kutukdjian, pp. 143-146.

the IBC and COMEST,⁷ holders of the UNESCO Chairs in Bioethics around the world, those in charge of national bioethics committees, members of UNESCO's Latin American and Caribbean Bioethics Network (*Redbioética*) and other eminent, independent specialists. As a result, we collected thirty papers from men and women hailing from almost all regions of the world, giving their views on the two main themes of the Programme: the legacy of the Programme's twenty years of existence, which gave the Programme its identity and essential meaning, and also proposals for lines of action for UNESCO's future role in bioethics.



During the first ten years of its existence, the content of UNESCO's Bioethics Programme has centred mainly on the directions laid down by the IBC, which has analysed and drafted reports on some of the most important fundamental themes of the discipline and also on our legal instruments. In the past few years, the Committee has continued to prepare and present the content of reference documents on the key principles of the Universal Declaration on Bioethics and Human Rights (UDBHR), and has supported the Secretariat in guiding the Programme. The following is a list of the most important reports in chronological order of publication:

Genetic Screening and Testing (1994); Human Gene Therapy (1994); Ethics and Neurosciences (1995); Bioethics Education and Teaching in the Americas (1995); Genetic Counselling (1995); Ethical Considerations Regarding Access to Experimental Treatment and Experimentation on Human Subjects (1996); Confidentiality and Genetic Data (2000); Use of Embryonic Stem Cells in Therapeutic Research (2001); Solidarity and International Cooperation between Developed and Developing Countries (concerning the Human Genome) (2001); Women's Rights and Bioethics (2001); Ethics, Intellectual Property and Genomics (2002); Possibility of Elaborating a Universal Instrument on Bioethics (2003); Consent (2008); Human Cloning and International Governance (2009); Social Responsibility and Health (2010); Report of the IBC on Traditional Medicine Systems and their Ethical Implications (2012); Human Vulnerability and Personal Integrity (2013); and Non-Discrimination and Non-Stigmatization (2014).

Without doubt, it can be said that the Programme's greatest achievement was the adoption by acclamation of the following Declarations by UNESCO's Member States during sessions of the Organization's General Conference: the Universal Declaration on

7 World Commission on the Ethics of Scientific Knowledge and Technology.

the Human Genome and Human Rights, in 1997; the International Declaration on Human Genetic Data, in 2003; and lastly, the UDBHR, in 2005. It should be noted that these are the only three international legal instruments concerning bioethics in the entire world.

Bearing in mind that these Declarations established the essential principles of bioethics, the second challenge for the Programme has been their implementation. Consequently, in parallel with the drafting, discussions and adoption of the Declarations over the past ten years, mechanisms have been set up to put the normative universal texts into practice and thus make the ethical principles a reality, as will be seen later on.

We know that the new possibilities brought about through science and technology present ethical challenges; however, it is in everyday society that we come up against the greatest dilemmas, facing issues of an economic, political or cultural level. The complexities of modern life create risks that call for the exchange of many views on the part of different actors. This is the 'dialogue procedure' of bioethical reality, which can be resolved through discussion and agreement. It is here that the most effective policies and local legislation can be introduced, because agreement is reached through confrontation and debate; these discussions among those with diverging opinions are the very foundation of the Programme's work.

Thus, the cornerstone supporting the application of the principles is the deliberation process of discursive ethics and the collective construction of opinions, within the imperative of respect for each other and for inherent differences. These discussions enable us to work on the free choice of the kind of society we wish to build, fostering three-way dialogue among experts, decision-makers and civil society, including professional bodies, legislators and representatives of the mass media. For UNESCO's Social and Human Sciences Sector, this public debate is the concomitant process that forms a fundamental, strategic link to guide knowledge, together with regulatory social action policies.

This kind of rational, intersubjective discussion for decision-making is characterized by respect for democracy and the avoidance of paternalistic approaches based on knowledge as power. Similarly, when confronting the damage inflicted by technocracy and macro-economics, participation, particularly if it is developed from the outset and is the basis of the decision-making process, creates a sense of belonging and helps nurture the principle of shared responsibility. As mentioned above, participation is developed in a context of plurality, comprising the principal actors involved in the ethical

issues on which decisions will be made, however different their views may be. Lastly, the public, ethical debate has to be rooted in the social circumstances of those present. As people find themselves at a crossroads of knowledge, technology, reason and reflection, the debate thus becomes a generator of social issues designed to shape the direction of future policies. It is on these four qualities – democratic, participatory, pluralist and social – that public debate as a method is founded.

The experience of negotiation on an equal footing and the exercise of pluralist, respectful, public debate strengthen social cohesion. It can also be argued that this is one of the most important contributions that the social sciences can make to the fair management of social transformations. The value the Bioethics Programme places on public debate lies not only in facilitating the implementation of universal norms or in guaranteeing the effectiveness of public policies, but also in the application of ethical practice, where a balanced consideration is given to the values and conflicts arising from established interests.⁸ Although technoscientific possibilities for the basic manipulation of life have a significant symbolic dimension, involving different cultures and world views, it is not only cultural practices that inform ethics but also social, political and economic conditions. Ethical thinking, in order to be aid decision-making, has to be sufficiently robust and, given this dialogic process, it can be.

With regard to the above, the Bioethics Programme gives priority to personal and professional training as the key means for the effective implementation of these debates. Therefore, teaching modules are provided for both students and teachers⁹. These modules are interdisciplinary, covering epistemological and methodological perspectives, the aim of which is to train bioethics experts and facilitators from the general academic field, not exclusively those from medical faculties, looking towards institutions teaching biology or health, in addition to non-academic spheres such as politics, government, legislation and, above all, social action.

The second pillar of the Programme is institutional capacity-building and helping to set up National Bioethics Committees in those countries that have requested UNESCO's support. These committees have two main functions: firstly, to advise decision-makers, particularly those who draft legislation and policies relevant to the regulation of the various bioethical dilemmas that arise in

8 See G. Papanagnou (ed.), 2011, *Social Science and Policy Challenges: Democracy, values and capacities*, Paris, UNESCO.

9 Core course in bioethics and Ethics Teachers' Training Course.

local and national contexts; and secondly, to promote bioethics training and public debate, in addition to open, inclusive methods of considered action.



Let us consider first of all two unavoidable precedents: contemporary life, where discoveries and technology seem to offer us the possibility of doing more than ever with regard to life itself, presenting us with two major challenges: knowing what to do when faced with new knowledge and how to behave when faced with social changes on values, principles, beliefs and institutions. Here we have two of the most fundamental questions of philosophy: What should be done? And, above all, What is Man?

Returning to Federico Mayor's warning: 'knowledge is always positive but its application may not be', when faced with the whole range of new technological possibilities, we should proceed by only applying that knowledge in the right way (an essentially ethical statement). In addition, faced with problems that may lead to a wrong application of this knowledge, UNESCO's prime interest is universal public regulation, or at least the provision of an overall governance framework that designates the limits of responsible social action.

The quality of life bound together with the common good make up the circumstances of the human being; they are fundamental to the importance of human dignity, particularly from the social point of view. As stated in one of UNESCO's Declarations: the human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity. Symbolically, it is the heritage of humanity and cannot give rise to financial gain (such as the reproductive cloning of human beings), because that would constitute a serious assault on human dignity and individual genetic heritage.¹⁰

Certain principles must be taken into consideration with regard to the dilemmas that technological possibilities present for humanity in each of these areas. Within the framework of its Programme, UNESCO's work on bioethics aims to include the consequences of the techno-scientific development in a society that we would like to see develop, taking into account the essential question of human nature, from conception to death, and rethinking the relationship between techno-scientific knowledge and human values. The study of bioethics also aims to clarify fundamental approaches in order to help solve concrete problems such as, for example, access to the

10 *The Universal Declaration on the Human Genome and Human Rights*, Articles 1, 4 and 11. See also the article by G. Kutukdjian in this book, pp. 143-146.

benefits of science. In order to do this, the focus needs to be on the methods and procedures outlined above.

Thus, the purpose is twofold: to build a framework of reference that regulates and provides guidelines for the governance of technical and scientific knowledge, in addition to providing social clarification on ethical alternatives. It is clear that ethics, like philosophy, is ontologically open and works through the posing of questions on subjects which do not easily allow for a regulatory framework; but since bioethics also comprises behaviour (the ethical dimension), individual decision-making and politics (regulations and governance), it requires a normative, potentially open framework. Given this operational perspective, it is difficult to claim an exclusively philosophical or scientific focus; rather, it is situated more at the crossroads of knowledge, technology, reflection and reason. Bioethics operates outwards, from the debate at its centre, generating a shifting puzzle with regard to social awareness and policies. When scientific knowledge and technology affect society, then a real sense of social belonging is achieved, in the broadest sense of the term.

All of the above shows why, from the beginning, UNESCO placed the Bioethics Programme within the social and human sciences, historically alongside philosophy and human rights.



As part of the twentieth anniversary of UNESCO's Bioethics Programme, we have provided a brief overview in this Introduction: historical roots, epistemological coordinates, as well as function, in line with our institution, intentions, assumptions and potential. The content of this book is deliberately not homogeneous. Nonetheless, it presents a converging diversity in the sense that it is a piece of work that opens onto a continuous process of refining. In this book, the thirty authors take distinct positions, encouraging extensive debate with regard to bioethics. For this particular publication, the contributors were invited to offer their reflections on two themes: the significance of this Programme after twenty years and new trends that could develop in the near future.

Most of the contributors wrote on both subjects. But some of them also developed a historical narrative on bioethics as a discipline or as a field of study, while others preferred a more theoretical or methodological approach, touching on numerous areas within the current debate on bioethics; almost all focused on the importance of the UDBHR. Finally, some contributors included elements of social or geo-political contextualization and others proposed new subjects for consideration by the IBC.

The contributions received were grouped into four sections. The first concentrates on bioethics in UNESCO (conceptual and global vision); the second on philosophical and normative attributes; the third focuses on some specific aspects and fields of application and contextualization; and the fourth looks towards the future, with topics that could present key challenges for the Programme, both institutionally and as a discipline. In order to determine the section for each article, we took into account the central theme of each. Therefore, the fact that they are in a particular section does not imply that these chapters focus on a single subject, since the majority of them deal with more than one of the four themes. In the first section, the reader will find a description of how bioethics came about and how its academic institutionalization began; debates against a narrow view and in favour of a more basic one; elements that are now considered to be classic in terms of the principlist or meta-principlist view; and the importance of including the gender dimension and of contextualizing problems including social, environmental and multicultural opinions, in order to create a global view of bioethics.

The normative section considers the philosophical and legal aspects. Here, reflections are offered on the role and the reach of normative instruments in general – and those adopted by UNESCO in particular – as well as on its philosophical and legal background. Also included here are studies that emphasize the normative contexts of bioethics, such as human rights, and the relationship between axiological universality, cultural diversity and plurality.

The third section groups together reflections, descriptions and proposals on more specific subjects such as: contextualization, personalized medicine, access to the benefits of techno-scientific progress, social justice and poverty, the right to health, intellectual property, the brain-drain and, *inter alia*, the emphasis given to vulnerable groups of people.

Finally, among the potential challenges of the future, the following are grouped together in the fourth and final section: the familiar trans- and post-humanism, the convergence of technologies, regenerative medicine, synthetic biology, ageing and environmental ethics. Also included are suggestions on international consolidation and the strengthening of training in bioethics. Some contributors offered particularly thought-provoking ideas with the titles of their articles: ‘The pending agenda’ (Keyeux), ‘The bio-philia future of bioethics’ (Sagols) and ‘Bioethics needs bayonets’ (ten Have). The final section concludes with the more defined, positive and promising idea of an agenda for global bioethics, the title of this publication.

Within this structured diversity and beyond its division into four sections, the reader will find thought-provoking discussion with regard to some of the fundamental problems of the nature of bioethics as a discipline, the aim of which is not simply a noble and pure philosophical discussion, but to determine the right way forward for the future development of UNESCO's Bioethics Programme.

Thus, for example, there is the recurring doubt about whether bioethics is a basic discipline or whether it is simply a technique of application. First of all, as we will see, the arguments proposed and defended confirm that bioethics does not belong solely to epistemology through its research vocation, but that it is also deeply philosophical, sharing with the latter two of its initial questions: What should I do? and What is Man? (Sagols). Secondly, its operational value should be emphasized, which is not instrumental, since reflection and application are closely linked both at the level of bioethical discernment, in the historical and local context of the dilemmas and in the holistic process of decision-making (Rawlinson, Keyeux, Stanton-Jean, Bergel, Touré, Kemelmajer). Thirdly, complementing this discussion, is the question of whether bioethics is an empirical discipline, an applied ethics or an individual ethics. If ethics is considered as a critical reflection on the principles that guide decisions and behaviour, then it might be inferred, by some contributors, that worthy bioethics belongs to the domain of moral philosophy and not to applied technology. With regard to our Programme, its instrumentalization is definitely not recommended, as this would reduce it to a purely reactive function. It is noted that bioethics, as understood by the IBC, can be more than that: both a timely and profound reflection on means and ends, while maintaining its critical function. For its part, this strengthens the crucial, original role of the Committee, a major space for reflection on the purpose of our societies (Semplici, Darwish, Yuthavong, Junges, ten Have).

It can be summarized that the contributors opted for three overall themes: firstly, the operative value of bioethics as ethical thinking, taking into consideration the historical and local contexts from a holistic standpoint. This approach appears particularly pertinent when one considers that the reality to which we need to pay attention is multicultural, socially diverse and economically unequal. Thus, these articles encourage us to deal with all social conditions, culturally, politically and economically, despite their being both distinct and part of a greater whole, as none of these dimensions alone is sufficient to explain reality.

The second recurring subject of debate, presented by the contributors, is that of the hermeneutic position of bioethics, moving between, universalism and what other contributors have

seen as ‘intersubjectivism’¹¹ in the context of plural societies such as our own, where we need to tolerate and respect the reasoning behind different views, even though we might not share them. On the other hand, within the realm of this discussion, some contributors mention relativism, doubtless due to the emphasis that the Programme’s implementation gives to historical and local ‘contextualism’. Nonetheless, given that, methodologically, this happens at a later stage, it would appear that there is no ambiguity in the universalist connection of the authors. Finally, the reader will also find suggestions on the right place for values, principles and laws in an open discussion, and on the manner in which the limits for debate should be set for these subjects. (Fournier, Casado, García, Penchaszadeh, ten Have). The main topic of discussion is the comparison between the principlist and the casuistic approach (Callahan, Sagols Bergel).

The three Declarations, particularly the UDBHR, are clearly of interest for everyone. From these contributions, two characteristics of UNESCO’s Bioethics Programme can be understood. Firstly, as we have already seen, the fundamental referent of ethics is universal, enshrined in human rights, as set out in the Declaration adopted by the United Nations General Assembly on 10 December 1948 and, consequently, recognized globally as rights which are indivisible, intrinsic, universal and inalienable. This ‘moral and legal minimum’ that universally binds us, is the guideline adopted to resolve conflicts in our globalized and necessarily diverse world. Secondly, within the holistic approach of bioethics, a social focus is preferred; the UDBHR has clearly established the social focus of bioethics, particularly in Articles 10 to 15, which define its fundamental principles: equality, justice, equity, non-discrimination, solidarity and cooperation, along with social responsibility and health (Bergel, Gluchman, González, Guessous, Kirby, Martin, Mayor).

In conclusion, the recommendation is at once normative, procedural and inclusive. In order to overcome instrumental reduction or partiality towards a comprehensive approach, a commitment must be made to bioethics at the global level. The central approach is rooted firmly in shaping bioethics at the international and general level. As shown in the current debate, global bioethics is not a new or specific field of analysis, but one that considers issues at the heart of ethics, and which calls for a transformation of the discipline in general (Kutukdjian, Rawlinson).¹²

11 A. Cortina, 1986, *Ética Mínima, introducción a la filosofía práctica*, Madrid, Tecnos.

12 D. García, 2014, History of Global Bioethics, in H. ten Have and B. Gordin (eds), *Handbook of Global Bioethics*, Springer, Netherlands.

The reader now has thirty contributions to consider. Naturally, we hope it will interest all our friends and work colleagues, the members of our various committees, from the U.N. Inter-Agency Committee on Bioethics to the members of the National Bioethics Committees and the UNESCO Chairs in Bioethics. We also hope the book will catch the attention of everyone who is interested in bioethics, whether they are a specialist or not: scientists, not necessarily biologists or medical doctors; social scientists, civil servants, politicians in general and, above all, citizens taking responsibility for the future of all human beings.



Producing a collective work involves the cooperation and dedication of many people: first and foremost, the eminent specialists who, despite their numerous responsibilities, agreed to take part as contributors to this publication, respecting the specific demands and deadlines. Also Dafna Feinholz, whose depth of knowledge, integrity and respect for the others see her lead UNESCO's Section of Bioethics and Ethics of Science with lucidity. Secondly, I wish to thank Rosemary Wiltshire, the translator from French and Spanish into English, and reviewer Julie Wickenden, who carried out their excellent work with the legendary discretion of their profession. And lastly, I wish to thank all those members of the team in charge of editing and publishing in the Social and Human Sciences Sector and in the Bioethics and Ethics of Science Section in the UNESCO Sector of Social and Human Sciences: Gloria Madriz, Patrick Bradley and April Tash; Saïma Vahekeni, Daniel Arbaiza-Rodríguez, Viviane Wu, Othman Boucetta, Michelle Bayefsky and Sudeep Rangi. I am indebted to all of them, who at different stages along the way have given generous, versatile and professional support to this enterprise. All their efforts are sincerely appreciated.



PART ONE

Conceptual and Comprehensive Vision

Bioethics: its past and future

Daniel Callahan

President Emeritus of The Hastings Center, New York, USA, and the author most recently of *In Search of the Good: A Life in Bioethics* (MIT Press) and *The Roots of Bioethics* (Oxford University Press, UK)

At a Christmas party in 1968 I asked a friend – Willard Gaylin, a psychiatrist who had written on a wide range of social issues – if he would be interested in helping me start a research centre on medical ethics. He quickly agreed.

We called it medical ethics, using the older term a few years before the term bioethics was even coined. It soon became clear that a number of emerging issues in biology and medicine went well beyond the historical scope of the ethical traditions of medicine: organ replacement, genetics, behaviour control and modification, among others.

Neither Gaylin nor I had either run anything or raised money, and most people had never heard of the medical developments. There were, moreover, only a scattering of people in research or medicine interested in the ethical problems generated by the rapid technological innovations that emerged in the aftermath of World War II, but particularly in the 1960s. I had been trained as a philosopher, but found the reigning analytic philosophy boring and dry, often far-removed from human experience. The terrain of the ethical dilemmas of medicine and biology offered the perfect antidote.

However, an informal network of people interested in medicine, biology and theology was gaining ground, and at least for the early years of the 1970s, we were at the centre of that (only a little later did we become aware of a parallel movement in the UK, led by Raanan Gillon, among others). We agreed early on that the field and our centre should be interdisciplinary, not dominated by any one discipline. My early interest and that of many scientists interested in ethics was that of some deep and fundamental questions about the medical and scientific developments. A three-fold question came to the fore: What were the implications of those developments for the future of medicine itself, for our understanding of the nature of health and human welfare, and for the way people would come to understand themselves and live their lives? I call that the first stream of bioethics.

Then a second stream quickly emerged, with a narrower and shallower agenda, one more focused on a wide range of immediate problems and with clinical legal and policy implications. It was to push the first stream aside. Those problems included the changing doctor-patient relationship, developing human subject research regulation, end-of-life care, prenatal screening, the first glimmerings of genetic engineering, in vitro fertilization (IVF), and organ transplantation. Another development was a growing interest by philosophers in the field, drawn, as I was, by a desire to do more work in applied ethics. In a short time, they usurped the earlier domination of religious ethics in the history of medical ethics.

The philosophers brought with them, moreover, an interest in ethical theory. Bioethics, it was said, could not advance as a field unless it had a solid theoretical foundation. It was in the 1970s that, if not quite an overarching foundational theory, the 'principilist' position emerged, specifying four philosophical principles as a basis for moral decision-making: respect for persons, non-maleficence, beneficence and justice. While this approach always had its critics (of which I was one), it soon became dominant in bioethics and was taken up as enthusiastically in the U.K. as it was in the U.S. In the 1970s, too, the first of a series of government councils and commissions on bioethics was formed. Unlike many European countries that eventually established permanent national bioethics commissions, those in the U.S. have been short-term, a new one being established by each new President.

By the end of the 1970s, a number of developments had occurred. The Hastings Center had been joined by other bioethics centres, notably the Kennedy Center at Georgetown University, but also by small centres in many medical schools. In those schools also, courses in bioethics had proliferated (sometimes still called medical ethics) although they were not always welcomed by older medical school faculty members. They felt it threatened the doctor-patient relationship and they resisted the meddling of philosophers and lawyers in their domain. Human subject research requirements, increasingly more detailed, were often resisted by medical researchers. Courses on bioethics also became popular at the undergraduate level, which saw a proliferation of text books and collected essays appearing to meet that need. One textbook came to play a dominant role, *Principles of Biomedical Ethics*, now in its 7th edition, edited by Tom Beauchamp and James Childress, both of whom had a major hand in devising and further refining the four principles over the years.



As time moved along, the Hastings Center grew and flourished, as did the field as a whole, helped in great part by a strong media interest and particularly by a number of prominent court decisions. Early on, the Hastings had four areas of special interest, each chosen because we believed they would be enduring in the field: population and reproductive biology, behaviour control by medical and other means, end-of-life care, and genetics. And endured they have. When some 40 years later a new President of the Center, Mildred Solomon, helped to fashion an updated set of issues as focal points, it remained very similar to the older ones: the self and the neurosciences, end-of-life and care of the aged, humans and nature, health policy, children and families.

Perhaps the greatest addition was that of health policy, greatly stimulated by the debate on American health care reform. Yet the professional world of health policy, dominated by economists and technically trained policy analysts, has been difficult for bioethicists to enter.

Save for occasional issues of justice and health care rationing, there is little explicit interest in ethics as a discipline of use in managing health care systems. Ironically, that was also once the case in the early years of bioethics when those trained in philosophy, steeped in conceptual rather than empirical analysis, tended to pay little attention to the social sciences. Those in the latter fields noted that omission and complained loudly about it.

Yet the social sciences were eventually to triumph, a change that provides a transition point from the early decades of bioethics. That triumph was marked by the phrase 'empirical ethics', which rapidly came into play during the past decade or so. It marks an effort to bring together philosophical analysis and empirical evidence. Sociological, anthropological and psychological studies proliferated, drawing a number of researchers from those fields. Just whether that shift reflects a tacit deference to the cultural domination of science and the diminution of the humanities (at least in the U.S.) is itself an interesting social science question.

A prominent Physician-Bioethicist, Ezekiel Emanuel, once told a large gathering of bioethicists that they would not be able to get grants from the National Institutes of Health if they did not incorporate empirical elements.

The triumph of social sciences was marked by the phrase 'empirical ethics' which rapidly came into play during the past decade... It marks an effort to bring together philosophical analysis and empirical evidence

Another recent trend that has caught my eye may have some bearing on the meaning of the empirical trend. For many years philosophers had, as noted, sought to find a firm theoretical foundation for bioethics. That has never happened and the issue has all but disappeared. Most of the many physicians and lawyers now working in the field have little interest in the foundational questions that once bemused, and sometime obsessed, philosophers. Even many of the philosophers have tired of that debate, finding that one can get along well enough in ethics in the absence of big theories. In my own case, concentrating lately on questions of policy and the relationship between ethics and politics, the problems are multi-layered – some layers inviting a utilitarian approach, other layers deontological, and still others something else again. What have been called ‘wicked’ problems – those marked by sharp ideological and political differences, fuzzy lines between scientific knowledge and the use of that knowledge in fashioning public policy and clashing rhetoric – do not lend themselves to some magic bullet theoretical foundations.



What is the future of bioethics? That is a good question, but one that does not lead to many safe predictions. One of them is that many of the earliest issues are still with us and will remain so for the future. There may well never be a final conclusion to end-of-life debates, complex genetic developments and ensuing clinical and policy arguments, expensive health care for the chronically ill elderly, and even definition of death puzzles. One reason for the enduring nature of those issues will simply be new scientific knowledge and new angles of interest from a younger generation. Whole new sub-specialties will emerge, as neuroethics has done. A glance at any of the journals of bioethics will now reveal a mix of old and new topics.

I will end by mentioning one trend that I find disturbing. In the early years of bioethics, there were few journals in the field, and no interest on the part of academic presses in publishing a bioethics book. We had no choice but to write for an educated public and gain a toe-hold in the trade press and a few medical journals; and that was stimulating for us and for the field. But bioethics has become an academic sub-specialty, whose journals are published by and for those in the field. The trade publishers, aiming for the educated public, no longer have much interest in bioethics. We now are forced to write for peer-reviewed journals and to get ourselves published by academic presses that often sell our books for \$50-\$60 (and a friend recently told me that a new book of his was priced at \$125), almost guaranteeing a professional audience only, if any. I don't count that as progress.



The bio-philial future of bioethics

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What can the future of bioethics be in a world characterized by a scarcity of basic natural resources, hunger, excessive over-population, the global ecological crisis, multiple financial crises, migration and unaccepted multiculturalism, the risk of nuclear disasters, a permanent state of war, the use of chemical weapons, the threat of biological weapons, economic and techno-scientific globalization and the superiority of North over South? Under what conditions can bioethical theory and practice be successful in health care?

It is essential to bear in mind that bioethics came about on the one hand in an ethical context of liberation and affirmation of autonomy and human rights and, on the other, in an ethical context of extending equality to those groups traditionally discriminated against, including other living beings: the environment and ecology, and especially the larger class of mammals.

However, it became clear that at least in its first four decades of existence, bioethics placed greater emphasis on the first of these aspects than on the second. At the same time, it dealt far more with the medical and biomedical matters that concern the present and the future of people with decision-making capacity and the financial means to accede to the spectacular advances of biomedicine, than to the issues that lie in wait in the global context. The ordinary citizen and ecological issues took second place in those early years. This can be explained by the long rule of the principlist model, the liberal position, centred on the defence of the autonomy of the decision-makers. Of course, to the extent that the principlism includes the principle of justice, then it is considering equality, but only with regard to distribution of resources. But it is also true that other positions, beyond that of principlism, and which have placed emphasis on the social aspect, have spoken out for the protection of vulnerable groups and the excluded, in an attempt to seek inclusive, fair treatment, in addition to access to the benefits afforded by science and technology.

Nevertheless, bioethical thinking has been very slow to get to the bottom of the implications of extending equality.



An important milestone here is feminist bioethics, which has forced through some re-thinking on gender equality and the social disparity of power and has also managed to direct attention towards equality of the excluded.¹ At the same time, feminist bioethics have managed to broaden the spectrum of bioethical issues, drawing attention to medical inequalities and biomedical experimentation that endangers women's health, the difficulties in getting medical attention about their concerns (more than just informed consent) and being able to take into account the loss of autonomy in some patients, to stress the importance of relations and real life contexts, the importance of ensuring understanding through interpersonal dialogue and, together with this, advise on the relevance of literature and narration as favoured methods of explaining the subject of bioethics. Feminism has made bioethics reflect on the excluded in general, in their own context, in their actual situation which is far removed from those who hold power, and not only look upon them as mere holders of rights for access to health and progress. Thus, feminism has brought with it a revolution in the content, ideology and bioethical methodology, which is no longer just reflection on autonomous subjects with formal rights. Nor does it merely follow principlism

Bioethical methodology can no longer be applied ethics; it must be comprehensive ethics that goes forward in close connection with other humanistic disciplines

and rationality; on the contrary, it has acquired the authority to include the vulnerable and the excluded. It has carried out a 'civic revolution'² that aims to respond and get closer to the 'ordinary person'. This is made clear in the UNESCO Universal Declaration on Bioethics and Human Rights, which is essentially inclusive. At the same time, bioethical methodology can no longer be applied ethics; it must be comprehensive ethics that goes forward in close connection with other humanistic disciplines³

1 See, for example, H. Brody, 2008, *The Future of Bioethics*, Oxford, OUP; T. López de la Vieja, 2008, *Bioética y ciudadanía. Nuevas fronteras de la ética*. Biblioteca Nueva, Madrid.
2 López de la Vieja, *ibid.* Third section. pp.259-60.
3 Brody, *ibid.* chapter 6, p.114.

with the emphasis on continuous revision of decisions made in Committees.

Bioethics has striven to attain inter-human equality. But if it wants to have a successful future, each step must take it closer to attaining equality for all beings and it must emphasize ecological issues and the limits thus incurred for human behaviour. War, malnutrition, climatic change, depletion of natural resources and extinction of species involve serious deterioration of social and personal health as well as that of the planet. I am talking here of a complex inequality that involves more than one direction and cannot be reduced to homogeneity or uniformity. It is not a question of no longer being able to exploit any living being, but rather one of respecting the right of that species to continue existing.⁴ It is a question of basic equality of worth: in principle, no living thing should die, but on the other hand, some living things have to die so that others can live: the whole of life is shaped by prey and predators. The crux is that this will not mean a greater extinction of species because from the diversity of those species come the richness and renewal of life. The human being is an 'administrator': he/she must look after the survival of the forms of life and of the health of the Earth and, at the same time, must satisfy his/her own needs.

The events of today's world tell us that renewal of the Earth and its multiple living beings have deteriorated enormously. And that is because we humans have gone too far. It is essential that we stop wars and the destruction of life. To be in tune with the studies on peaceful societies,⁵ bioethics needs 'education for peace' and its own eco-feminism,⁶ to move towards bio-philosophy or love for life. Not the passive, formal peace that simply tolerates the right of the other to life as he/she wishes or simply seeks disarmament, but the true, active peace that proposes values which fight for justice and mutual understanding from the search for a better fate for humanity. Only then can we continue towards disarmament.

The obstacle facing this task was pointed out by Claude Lévi-Strauss⁷ and later on by Lynn White.⁸ It is rooted in Judæo-Christian tradition: anti-ethical anthropocentrism 'which makes us like God' and, for this reason, arrogant, violent, dominant, despotic, possessors of the Earth and sacred or supremely important. A good part of bioethics and the environmental ethical proclamation

4 A. Leopold, 2000, *La ética de la Tierra*, in *Una ética de la Tierra*, Catarata, Madrid.

5 H. Goettner Abendroth (ed.), 2008, *Societies of Peace*, Toronto, Inanna Publications, Inc.

6 F. D'Eaubonne, 1974, *Le féminisme ou la mort*, P. Horay, Paris; K. Warren, 2000, *Ecofeminist Philosophy*, Colorado, Rowman and Littlefield.

7 C. Lévi-Strauss, 1956, The three humanisms, 35:16 (Vol. 36), *Demain*.

8 L. White, 1967, The Cultural Roots of Our Ecological Crisis, in *Science*, 155, pp. 1203-07.

has been critical in this respect, but it has not got down to the fundamental issues because it has concentrated on making humans equal with superior species and has ignored the fact that with the exclusive sacred quality of human life, it established 'be fruitful and multiply' as culmination of the possession of life, without considering that we share the Earth with other living species. If we have failed as administrators of the Earth, it is because of our over-population and our condition of lords of the planet, which generates violence that is both inter-human and against other species. This over-population is anthropocentrism's hardest aspect to break with. It would seem that in criticizing it we are going against humanity, when in reality we are in favour of life.⁹

If something requires bioethics in order to have a future that contributes to the health of the planet and of humanity itself, then this means insisting time and again on the sacredness of all forms of life. So, organizations like UNESCO must put a good part of their efforts into education and the search for positive public policies that are neither punitive nor domineering in order to limit new births. For the future of bioethics to be bio-philosophical, it has to be egalitarian not through extreme feminism but through understanding equality.



9 The reduction of population excess is a task already pointed out by Van Rensselaer Potter, 1988, in *Global Bioethics*, Ann Arbor, Michigan University Press.

Bioethics at UNESCO: challenges and needs

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Globalization, the instantaneous dissemination of information of all kinds all over the planet and the alterations in geopolitical balance have brought about extraordinary transformations. Add to this a constantly growing need for strong impetus of a bioethical nature from credible institutions, both in the classic field of biomedicine as well as more broadly in terms of global change, including climate change and threats to the environment.

Reducing inequalities remains a fundamental goal. The rapid advances in science and the ‘marvels’ announced are certainly impressive and some of them nurture a fantasy of immortality. However, on the subject of bioethics, this should not mean available resources (intelligence, time, money) being disproportionately devoted to such issues. What matters is responding to the needs of the great majority of humanity. All over the world there is growing socio-economic inequality, both within and between countries. But until now there has been no positive response to this challenge and it is essential to keep moving ahead towards equity, while at the same time knowing how to be constructively critical of what has not worked.

With regard to inequality, we need to pay even greater attention to the situation of women and young girls. In many different ways, women continue to be disadvantaged with respect to opportunities for developing their potential. They suffer marked constraints on their freedom to live their own lives, particularly concerning decisions relating to procreation. Women do not have the same opportunities as men, and yet the share of the overall work carried out by women is often far greater than that carried out by men. In several legal systems, a woman remains a minor in the eyes of the law. In this regard we must become a more equitable society.

The tension between Me Medicine versus We Medicine. It might be useful here to refer to a book by Donna Dickenson. Under current growing pressure, this health and ethics specialist is leaning towards so-called personalized medicine (*Me Medicine*), a reflection on prevailing individualism, little affected by public health concerns (*We Medicine*). Faced with the super-fast evolution of the biosciences, she asks for diligent attention to be paid to the need to uphold and improve solidarity. With regard to the seeking of enhancement of the human being, it is clear that the practical prospects would be open to only a few. Dickenson asks the question: What would happen if we found ourselves in the situation of the disregarded *Lumpenproletariat*?

Individual autonomy and the common good. One permanent challenge is to find the right balance between the freedom of each person to behave as he/she wishes and the interests of the general public. Over the last fifty years, emphasis on a person's (patient's) self-determination has been a strongpoint in the evolution of medical ethics, both in the clinic and in research. And yet, concerning the common future of humanity, we find there are major difficulties in mobilizing populations and authorities to cope with these dangers. It is essential that we take another look, with no restrictions, at the objective and subjective tensions between the right of each person to do 'everything and anything' and consideration of the common

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good. We must keep in mind that the value we put on freedom only depends on the limits we are ready to place upon it and that many people today are not in a position to defend their legitimate interests. The libertarian ideologies that abound in some places constitute a real threat for the survival of a civilized global society, which poses the question: should there be one or several models of global governance?

Managing our Promethean urge. Humanity is Promethean. From a certain point of view, how can we but admire its will, displayed in so many ways throughout history, to increase its knowledge

and experience, to invent, build, discover and overcome obstacles? It is in our nature, but is it fate? If it is, then is that not tantamount to a suicidal trajectory, given current upheavals and destruction? Are we in future going to do everything that bioscience allows us to contemplate? In my view, it is simply not possible to deny that limits must be drawn; at least we might envisage some moratoria. The task of the International Bioethics Committee (IBC) and of the national bioethics committees is to say where barriers need to be set up and why. For example, even though there currently may not be a constraining instrument to enforce it, there is virtually unanimous opposition to reproductive human cloning. The aim being human dignity and the imperative to do no harm. Being civilized means placing limits and boundaries: on the power of the State over the people and on the undue constraints of one person over another. Will we lose our civilized nature if we refuse to envisage interdictions with regard to the application of technical potentialities?

Promoting the emergence of a homo ethicus and convivialis.

The *homo oeconomicus* model, for a long time the only one to have been placed in a conspicuous position as being the only one of any worth, is showing its limits and tendencies to go off course. Pursuance of short-term personal gain and exploitation of one person by another while disregarding harmful elements beyond their personal scope, put our lives in danger; this already applies to the present but particularly threatens our future. Everything points to our need to find ways and means for a global paradigm change, a change of heart. First of all, to do no harm: we know the Hippocratic injunction *primum non nocere*. Today it enjoys renewed attention; we distance ourselves from the medical activism that marked the twentieth century. Opinion leaders issue warnings saying it might sometimes be more useful if we did less (less is more). In any case, there is a need for more careful consideration of the negative effects that can be produced by initially well-intentioned action.

Economy and ecology, intersectorality and interdisciplinarity. Together with other institutions, UNESCO must pay greater attention to the relation between economy and ecology; these should no longer be in opposition to one another. There needs to be reconciliation between them by means of a change of perspective referred to earlier. The importance of teamwork, in the broadest and holistic sense of the term, is obvious. It is a matter of wanting joint action to be carried out by all the actors and institutions concerned. This could be done by making the best use of the competences of the various sectors: government ministries and

the public sector, corporations, NGOs and their associations, and civil society. Whether public or private, professional or not, general practitioners or specialists, charitable or profit-seeking, each one of these stakeholders can find a reason for cooperation.

UNESCO's Bioethics Programme, a vast educational activity.

This Programme must continue and be extended, *inter alia* by cooperating with the establishment of national committees provided with human resources and appropriate equipment. Support for the teaching of bioethics through the provision of training opportunities is of the utmost importance. Work conducted on bioethics is eminently inter- and transdisciplinary, and its committees are composed of personalities whose areas of specialization are varied: philosophers and experts in other human sciences; medical doctors; health professionals and biologists; lawyers; and others representing patients and civil society. One of the concerns in the work of these committees is that while they are inevitably confronted with opposing views, the overall aim is to listen to the other and have a respectful discussion, avoiding ideological confrontation which can happen when a number of pronouncements are made that may simply be non-negotiable for some of those present. It being understood that the discussion would not go so far as unwarranted relativism: the principles such as those inscribed in the Universal Declaration on Bioethics and Human Rights are fundamental points of reference. There is a great need for information and education everywhere on what is at stake both socially and ethically. Bioethics must be a strong component in syllabuses – at schools, universities and professional or general training courses. People often talk about education for responsible citizenship; soon it could even be a matter of education for survival!



Bioethics: a bridge to the future?

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In 1927, the German philosopher and educator Fritz Jahr published an article entitled *Bio-Ethics: A Review of the Ethical Relations of Humans to Animals and Plants*. In it he proposed the extension of moral regard to all living beings and emphasized the continuity and interdependence of human life with other forms of life. He articulated a 'bioethical imperative', basing ethics on the recognition of this interdependence and making humans responsible for preserving life in its diversity. His idea of bioethics takes a global and ecological perspective on biological science. Biology and medical science, he argues, require supplementation by ethical thought to ensure that they serve life, rather than undermining it or being hostile to it.

In 1970, the American biochemist Van Rensselaer Potter revived the term 'bioethics' and again identified it with a global concern for the integration of biology and ethics. He proposed bioethics as a 'bridge to the future', linking science to an ethic of life that would promote health globally. Potter understood ecology and environmental ethics to be central to the mission of bioethics. While no Luddite, he was deeply aware of the ways in which science and scientific progress threatened the environment and the quality of human life, and even human survival. Potter made a concept of sustainability central to bioethics, arguing for the incorporation of environmental ethics and the ethics of our relation to other animals into a global promotion of human health. Potter's 1988 text *Global Bioethics: Building on the Leopold Legacy* specifically linked human health to a respect for the land which sustains it.

In the four decades since the publication of Potter's *Bioethics: a bridge to the future* (1971), bioethics has become something more narrow and instrumentalist than the conceptual project envisioned by Jahr and Potter. Recent and contemporary bioethics focuses almost exclusively on problems raised by medical research and the use of new technologies in the clinic. UNESCO's own definition

of bioethics focuses on the ‘power’ and ‘progress’ of science and takes as paradigmatic problems for the field a narrow set of issues confined to the clinic and the lab: stem cell research, genetic testing, cloning. A survey of conference programmes and journal articles reveals the field’s focus on research ethics, concerns about property rights in relation to genetic material, the use of new reproductive technologies, or end of life issues raised by the use of exotic life-saving technologies. Funding opportunities for research in bioethics are equally narrowly focused on the ethics of research and the deployment of new technologies of medical intervention. The focus on consent in research or the manipulation of genetic data often seems to imply, as Onora O’Neil remarked in her 2008 address to the International Association of Bioethics, that contemporary bioethics is more concerned with liability and property than ethics.

Certainly, contemporary bioethics does not exhibit the broad concern with the conditions of life that was reflected in the work of Jahr and Potter. While Jahr and Potter were committed to reinventing the infrastructures of life to better promote global health, contemporary bioethics seems content to accept current economic, social or environmental arrangements and practices and to operate instrumentally within them. For example, the emerging obesity epidemic is approached as a matter of ‘health promotion’ with the idea that the task is to change individual behaviour. Almost absent in bioethics is any critique of the global food industry and the connection between the practices of agribusiness and the degradation of human health. Similarly, though data are readily available revealing the link

Discussions in bioethics of scarce resources or healthcare costs rarely undertake a critical analysis of current economic structures and policies, as they impede practices that would promote health.

between gender equity and the education of women, on the one hand, and community health on the other, the subjection of women is hardly a central focus of mainstream bioethics. Indeed, it is often argued that gender equity is a ‘separate issue’ and not properly included in rights related to health. Discussions in bioethics of scarce resources or healthcare costs rarely undertake a critical analysis of current economic structures and policies as they impede practices that would promote health. Bioethics seems, for the most part, to accept the current disposition of wealth and power and to operate within it, rather than seeing a lack of a political voice or social inequity as inimical to health around the globe.

This lack of a critical concept of power and a critical approach to capital and wealth leads bioethics to rely regularly on some form of cost-benefit analysis as a basis for ethical decision-making. Decisions about what counts as just coverage or access often turn on calculations of cost-effectiveness that are not well informed by an articulate idea of the conditions of human health and well-being. This leads to false choices and a merely reactive posture. Recent critiques of the cost of care for the elderly in the US have often cited the competing need to invest in prenatal care or the care of young children, as if this competition between young and old were a given, rather than an artifact of capital and the power of other economic interests. Approaches to obesity and related diseases regularly focus on medical intervention in the individual body, rather than the structural changes required to promote healthy eating.

Rather than accepting the *status quo* and reacting to proximate problems, Jahr and Potter understood bioethics to be a project of reimagining our global human future to promote human health and the interdependencies that sustain all life. Given the global degradation of the environment, the global explosion in obesity and other non-infectious diseases, the health risks to labour, and the rapid increase in social and economic inequity around the globe, it is imperative that bioethics recapture its original mandate as a 'bridge to the future'.



Three problems that have begun recently to claim more attention in bioethics prescribe a programme of action for the next twenty years. Firstly, the link between the subjection of women and the degradation of women's health has been clearly demonstrated, as has the positive effect on community health of investing in women's autonomy and health. When women in India receive less food and less care than their male relatives, their health suffers. When women in Saudi Arabia are prevented from engaging in physical activity, they suffer spiking levels of obesity and obesity-related disease. When women in the US are denied easy access to birth control and the full range of reproductive services, they suffer unwanted pregnancies and degraded reproductive health. On the other hand, investments in women's education and the promotion of women's economic independence regularly improve their health and that of their community. The Bioethics Section of UNESCO and bioethics generally need to practise the 'gender mainstreaming' prescribed by UNESCO's Division for Gender Equality. Gender equity is not a women's issue but a human issue, and promoting it is essential to human health and well-being around the globe.

Secondly, bioethics needs to make food central to its thinking. As infectious diseases decline, obesity-related diseases are spiking globally. Given the aggressive practices of agribusiness in marketing and controlling access to food, it is unlikely that isolated policies limiting sugar or fat will have much effect. Moreover, the practices of agribusiness threaten health through the reliance on chemical inputs and the extensive use of antibiotics in animal farming. The extension of agribusiness also results in the displacement of indigenous farmers and the undermining of local food economies, correlated with a variety of effects inimical to health, from the spiking suicide rates among Indian farmers to the explosion of dental caries in Indonesia to the massive urban migrations that create a host of new health emergencies. Bioethics should make central to its project a rethinking of how we produce, distribute and consume food: how and what we eat determines health.

Finally, a focus on food also raises the broader issue of environmental integrity and its relation to health. As the French philosopher Luce Irigaray has remarked, we are fast creating through our 'scientific progress'¹ a world that is inimical to our health. Not only is the security and wholesomeness of food threatened by the 'science' of agribusiness and its use of chemical inputs or antibiotics, but the availability of clean air and water is also at risk from science and progress. The air in the newly industrialized cities of China has become so dangerous that children are no longer allowed to play outside. Communities around the world find their water supplies at risk through the practices of global energy corporations or agribusiness. Bioethics needs to make central to its research a recognition of the dependence of life and human health on the integrity of the earth, its air, water and land.

By returning to the forward-thinking, future-oriented ideas of Jahr and Potter, bioethics would move beyond its narrow concerns with liability in research, the ownership of genetic material or the deployment of exotic technologies. By making gender and social equity, food and environmental integrity central to its research programme, it would address urgent matters that affect everyone globally. Rather than focusing on a narrow set of issues raised by 'progress in science' that affect only a limited and privileged segment of the global population, it could advance the structural and institutional changes that are essential to sustain human health. Then, bioethics might become a 'bridge to the future'.



1 See, for example, L. Irigaray, 1993, *Your Health in Je, Tu, Nous: Toward a culture of difference*. New York, Routledge.

UNESCO Chairs in Bioethics and their future task

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As part of its new strategic focus, UNESCO is trying to create think tanks at universities and research centres whose aim is to build connections between science and research on the one hand and civil society on the other, notably the link between research and the management of public affairs. The idea is to use the intellectual potential in UNESCO member countries both for the benefit of these countries and for the whole of the international community. The foundation of centres of excellence and the pursuit of innovation in the respective regions is one of UNESCO's strategic objectives.

In 1992, UNESCO set up the UNESCO Chairs programme, based on an Act passed at the 26th General Conference of UNESCO in 1991.¹ The Universities and research institutions that cooperate with non-profit organisations and foundations, in addition to the public and private sectors, are the most important participants in the programme. The aim is to enable university communities to collaborate with UNESCO to achieve the programme's overall objectives. The effectiveness of this cooperation is assessed at regional, national and international level. The aim of these activities is to support projects that seek to establish new educational programmes, to integrate new ideas within research, and to encourage cultural diversity by means of exchanges between academics, scientists and students.

I think that one of the 'think tank' tasks of the UNESCO Chairs in Bioethics is to clarify the fundamental terms and methodologies of bioethics. For example, when we look for answers to various definitions of bioethics, we are confronted with different views on its content, numerous methodologies and outcomes. Daniel Callahan, one of the most significant figures in bioethics and long-

1 UNESCO, 1991, Records of the General Conference, Twenty-sixth session, Paris, 15 October-7 November, p.33.

standing Head of the Hastings Center in the USA, starts his reasoning on bioethics by claiming, like the Bible's Solomon, that there is 'nothing new under the sun'. He goes on to say that issues of life and death, pain and suffering, law and the power to control one's own life including responsibility for oneself and others with regard to health and wellbeing, are among the oldest questions for humanity. In his opinion, bioethics is a radical transformation of an older area, i.e. medical ethics. He suggests that bioethics is not merely an intersection of ethics and sciences dealing with life, but also an academic discipline, as well as a vehicle for political decision-making in medicine, biology and environmental research, and it also provides a cultural perspective with certain consequences. In a narrower sense, bioethics is a new discipline which originated as a search for answers to new scientific and technological challenges. In a broader sense, it can, in his opinion, be described as an area which permeates law, politics, literary, cultural and historical studies, as well as popular media, branches of philosophy, religion and literature, and also to scientific spheres of medicine, biology, ecology, demography and social sciences².

Callahan accepts that the choice of ethical theory as a basis for bioethics is a subject for debate. In his view, it is a question of determining the credibility of the different arguments. Should we

Bioethics is not merely an intersection of ethics and sciences dealing with life, but also an academic discipline, as well as a vehicle for political decision-making in medicine, biology and environmental research, and it also provides a cultural perspective

take them seriously? Both groups, scientists and humanists, defend their views and standpoints. He, however, considers it much more important to reach agreement on practical issues in all areas, even without theoretical consensus. Moral decisions need to be made regardless of their theoretical foundations. According to Callahan, the authority of bioethics lies in a clear definition of the problem and the convincing argument of those who reflect on a moral problem. The primary task of bioethics is to clearly formulate a question which requires a solution, at whatever level, be it in clinical practice or at a political or legal

2 D. Callahan, 2005, Bioethics, in *Encyclopedia of Bioethics*, Vol. 1, Farmington Hills, Macmillan Reference, pp.278-79 and *intra* Daniel Callahan, pp. 19-22.

level... What follows is the study and reasoning behind the theories and the principles. It is, however, important to note that there are hardly any situations where a problem, which cannot be solved due to a disagreement between theory and principles, is also reflected in practice. This is also confirmed by the development of bioethics in recent decades. He points out that a good individual decision comprises three conditions: self-cognition, knowledge of moral theories and traditions, and cultural perception. Originally, bioethics was primarily considered as a matter of science, dealing with life by reference to issues of morality and values. This opinion has, however, gradually changed; sciences focusing on life are still at the heart of the question, but it is scientific rather than moral. Ethics plays a key role, as facts and values cannot be separated. Issues of moral value and the purpose of life sciences can no longer be separated from issues of moral value and purpose of society and culture.

In our view, his following proposal is of the utmost importance: even though bioethics is multidisciplinary, it still answers three fundamental questions: what kind of person should one be in order to live a moral life and to make the right ethical decisions? What are our obligations and engagements towards those whose lives may be influenced by our actions? How, as a member of society, can one contribute to common welfare or the public interest? I think we all agree that these three questions are primarily philosophical-ethical, and that they occur specifically in the search for answers to new medical and biological challenges. All disciplines which deal with issues of bioethics, whether in a broad or narrow sense, can help to answer them. In any case, ethics, regardless of the particular ethical theory it relates to, should be at the core, should serve as a starting point for reasoning, so that the solution relates to real, not imaginary, ethical and moral questions related to progress in biology and medicine, biomedical research and biotechnology.

Karl Raimund Popper stated on several occasions that it should be ideas that die in combat rather than people. I would like to modify Popper's statement, as I do not believe that it should be a matter of combat where ideas die, nor even a competition where there is a winner and a loser, but more a positive confrontation which gives rise to new ideas which may be productive in the search for shared present-day moral questions. One of the most important objectives of the UNESCO Chairs in Bioethics is to contribute to a positive confrontation and to the origination of new ideas, which might help to further theoretical development of bioethics in these countries, and to find new solutions to practical moral problems of bioethics and moral dilemmas of individuals with regard to issues of bioethics. I assume that we have a shared interest in solving these

problems, even though our methodological bases, the proposed means of solution, and the results obtained may differ. Let us not *a priori* reject other points of view on these issues and problems, let us not reject such thinking which might seem absurd, i.e. searching for answers and solutions outside of traditional or conventional ways of thinking. Nothing can be solved by 'burying our heads in the sand', rather the opposite. Let us not look for the one and only theory which could provide the only correct answer to the complicated ethical and moral problems of this era brought about by developments in science and technology. This has never, in the history of humankind, been possible and probably never will be, as long as humankind keeps its current form and nature. Let us clearly formulate questions or problems and let us argue and look for solutions to them in accordance with the principles and values of humanity, human dignity and the moral rights of humankind for life. Together, they should bring primarily positive consequences (also at a social level), or more positive consequences than negative, as the development of science and technology is often contradictory; or at least minimize unexpected negative consequences, which might result from the process of scientific development and discoveries. It is the only course befitting ethics and bioethics in all its forms in the twenty-first century.



Clinical ethics: another way for UNESCO to train people facing bioethical issues

Véronique Fournier

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UNESCO plays a fundamental role in helping people acquire skills in order to face new bioethical issues that constantly emerge, due to technological innovations in the field of medicine or science, or as a result of sociological changes in the way people intend to conduct their lives – and deaths. Much has been done in this field, through very interesting and relevant academic courses and general sets of ethical recommendations, which are now available to anyone intending to be trained in bioethics.

Our own experience in clinical ethics leads us to propose that this first level of education in bioethics be complemented by training people to deal themselves, in their own local contexts, with the ethical disputes that arise daily in clinical settings. Indeed, it is fascinating just how important the social and cultural context is in such matters. Universal guidelines and recommendations in bioethics need to take those local contexts into consideration, otherwise they may be less accurate when applied to specific cases. Furthermore, trained people, while becoming more actively involved in developing their own ethical matrix for clinical medical decision-making, should feel more democratically creative and ready/happy to discuss their similarities and differences with others on such universal issues. It should increase their capacity as ‘agents’.

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Too often, ethics seem to be giving a definite answer to difficult questions that might better remain without precise answers. One of the referent ethical matrices, used by clinical ethicists to analyse the ethical disputes that arise in the daily clinical field is the principlist matrix, first developed by Beauchamp and Childress in their celebrated work *Principles of Biomedical Ethics*.¹ It consists of evaluating a decision using different principles – respect for autonomy, the balance between benefit and harm, the principle of justice – before asking which argument has the greater weight in this particular case. Of course, the relative weight of each argument might vary according in different contexts, such as the importance of the family dimension, the availability of the best treatment, or if the significance of informed consent in the cultural background in which the dispute emerged. For example, the ethics of transplantation with living donors cannot be considered in exactly the same way in developing countries as in developed western countries, because access to cadaveric transplants is not the same, and because access to psycho-social support for living donors in such places is scarce. Another example is the risk of commodification of women's bodies, which clearly varies between different countries, with differences that might change very quickly from one context to another. The argument should be evaluated differently within the referent ethical matrix according to the reality of the local risk. Thus, ethical recommendations could come to radically different conclusions from one place to another, for example access to reproductive technologies such as surrogacy or oocyte donation. More importantly, local actors will have a stronger voice if they design and defend their own ethical matrices, rather than imposing a top-down, universal one. Moreover, it will offer a greater opportunity for local actors' voices to be universally heard, as new ethical challenges emerge from diverse local clinical settings and are discussed transnationally.

To conclude, it seems that training focused on clinical ethics could be relevant as an additional course to existing UNESCO ethics training. It would give local specialists the opportunity to further consider the ethical values embedded in their own context, to re-evaluate them, and to design an ethical matrix more specifically tailored to their environment. It would also enable them to become influential members in the field of ethics, which will be further strengthened if it is more democratically shared.



1 T. Beauchamp and J. Childress, 2009, *Principles of Biomedical Ethics*, New York, Oxford University Press.

Twenty years of commitment: the pending agenda

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Genomic medicine, genetic perfecting, nutrigenomics and in general all biotechnological advances that lead to designing boosted or enhanced human beings, called 'post' or 'trans' humans, are social and scientific challenges that will doubtless be on the agenda of the International Bioethics Committee (IBC).

Every scientific advance is accompanied at the same time by ideologies that instrumentalize its true advance and impact for powerful interest groups. Four decades of developing techniques of genetic manipulation in humans, from the reductionist approach derived from the biology of micro-organisms, provide us with great lessons and a warning to be distrustful of the myths and hyperboles expounded by powerful interest groups, who decontextualize issues that are characterized by a complexity of biological, socio-economic and cultural factors acting in synergy at various levels.

The line between repairing functions and the boosting of performance is a tenuous one. That is why we should keep our eye on the prioritization of universal access to proven technological developments which respond to needs and demonstrate benefits for patients being offered improved refinements, which in fact often do not turn out to be the promised Utopian dream, and in any case are reserved for the few with high purchasing power. Along these same lines, the advances in genetically engineered machines, where the principle of environmental benefit, including human beings, is often in conflict with the profit motive and the damage incurred by whoever imposes the market monopoly of the new genetically engineered organisms. This will doubtless be a subject for bioethical scrutiny in years to come.

Meanwhile, towards the end of 2013, over 8 million children came into the world with congenital malformations and serious

genetic disorders, and a further million were born with physical defects caused by maternal exposure to tetrazolium. Altogether, it is estimated that there have been over 100 million births with these

Congenital defects and genetic illnesses are not so much illnesses of the genes but of poverty

genetic conditions since 2001, the year of publication of the draft human genome sequence, without the cure for any of them yet being found. The impact is particularly serious in low or middle income countries, where 94% of babies are born with these conditions. Instead of decreasing, these figures are rising because of the increase in the global population, particularly in the least developed regions of the

world. Still more significant is the 95% of deaths occurring in poor countries because of congenital defects, and the majority of those who survive are seriously handicapped both mentally and physically for the rest of their lives. They live in societies where medication and therapeutic support are inaccessible, and the burden of care and responsibility falls predominantly to the mothers.

It is indisputable that congenital defects are socially determined: 90% of these children are born in poverty-stricken homes where living conditions are insalubrious, with parents who have a low level of education and where local services provide minimal packages of health care for the poorest and most vulnerable. Congenital defects and genetic illnesses are not so much illnesses of the genes but of poverty. Experience gained over the past fifty years in high income countries shows that mortality and incapacity caused by congenital defects could be reduced in lower income countries by 70% if measures were taken – relatively simple and low cost, but having great impact – which would include preventive education, providing ante-natal diagnoses and advice prior to conception, through to early access to required treatment. There could thus be a lessening of the stigma, discrimination and exclusion so often suffered by women who are the ones on the front line with responsibility for health, coping with their families and society.



“Theory itself does not change the world. It can contribute to its transformation but for this to happen, it must step out of itself and become assimilated by those who through their real, effective action, will cause such transformation to take place”.¹ That is

1 A.S. Vázquez, 1977, *Filosofía da Práxis*, Rio de Janeiro, Paz e Terra, p. 206

precisely the task of the IBC: to contribute to the implementation of action while ensuring that its discussions materialize into concrete action which brings global solutions to the issues confronting living beings, including humans, through harmful human action and the disregard for public health issues that require prompt action; in particular, helping to guide research and technological development towards the production of low cost diagnostic systems, scarcity of medication, therapeutic and nutritional support that are either not on the market or whose costs make them inaccessible to the poorest people, with the aim of reducing the 10/90 gap that also affects the resources destined for congenital defects.

Thus, another task of major importance for the coming years falls to the IBC: to ensure that education and access to the advances of science be effective. The political exercise of justice and equality is inseparable from access to knowledge and is constructed on empowerment. Therefore education, capacity-building and empowerment, particularly of women, will make it possible to eradicate the situation that prevails in developing countries through lack of prevention, ignorance with regard to intervention options and inequality of access to quality health services.

In addition, the civic process of social appropriation of rights in relation to access to advances in science, particularly genetic and genomic advances, is essential. Coordination of the work of experts on gender, genetics and bioethics and communication media, who may tackle specific needs of men and women in this field in a differential manner, will allow citizens who have the last word on these vast possibilities – and also dangers – that biotechnology currently has to offer, need to take up position and democratize the procedures of decision-making and confront the economic and political interests that accompany biotechnological innovation.

To sum up, the pending agenda for the years ahead involves the coordination between reflection and the global application of bioethics, in a way that includes environmental, social, multicultural and gender aspects and which, while respecting nature as intended by Potter, would be able to integrate the local and regional reality of the problems with concrete solutions in societies with varying levels of development.



PART TWO

Philosophical and Normative Applications

Dignity as the foundation for all Human Rights

Federico Mayor Zaragoza

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Director-General of UNESCO (1987-1999) and instigator of the Bioethics Programme in the Social and Human Sciences Sector

Is everything feasible ethically admissible? No. Is it permissible to use any instrument for the whole range of its possible applications? No. Knowledge is always positive. Its application may not be. Indeed, it may be perverse. That is why ethics has become so relevant, especially with increased knowledge and because of the influence of economic interests on its continuous use.

The elements that have a major impact on a personal and social level are those concerning bioethics, since human dignity and equality are the foundation, the cornerstone of duties and rights. However, science has continued to advance in all areas. For this reason, UNESCO initially set up an International Bioethics Committee (IBC) and later, a World Commission on the Ethics of Scientific Knowledge and Technology (COMEST).

The issues discussed are often very sensitive and controversial, therefore it is essential to maintain scientific rigour. In this kind of debate, all the speakers need to have the highest conceptual accuracy: scientists must express themselves clearly and ensure unequivocally that in all future scenarios they have taken into account the interfaces between what is feasible and the respect for the dignity of all human beings, the ultimate point of reference; politicians must leave their ideological biases aside and listen with the greatest objectivity to the arguments being presented; and representatives of different religious cultures must fully use their ability to reflect within the essential framework of their faith, without becoming confused by subjects beyond their field.

I remember one seminar held at UNESCO in 1985, on 'Genetic Manipulation and Human Rights', when I became aware of the need to tackle highly complex issues that required, through conversation

and the exchange of views, a definition of the areas and the coordinated identification of what should continue to be discussed.¹

Retrospective. The voice of the scientific community was soon raised, alerting people to the risks and perils that might be incurred in certain experiments on genetic manipulation, at both micro-organism and animal level, as well as that of human beings. These issues were debated at length at national and international level over the years, leading to the drawing up and approval of norms that aim to define the limits of application for techniques resulting from this new knowledge.

The basic ethical reference is Human Rights which are indivisible, inherent, universal and inalienable. But there is one right, the right to life, which takes priority, because the exercise of all these rights

The basic ethical reference is Human Rights which are indivisible, inherent, universal and inalienable. But there is one right, the right to life, which takes priority, because the exercise of all these rights presupposes life

presupposes life. In a lucid, extensive reflection on the ethical principles of life, Noëlle Lenoir, a lawyer who chaired the International Bioethics Committee, underlined the need for extending the concept of protection of the person to that of protection of all forms of life. Since 1948, the principle of 'respect for life' has gone through substantial changes in meaning. From 1970, thanks to significant medical

advances with regard to the first stages of life, respect for human life before birth was introduced. The development of ecology at that time emphasized the relationship between the human species and nature and widened the arena of respect for life with a basic principle of legal protection for 'the living' as a 'whole'.²

In *New powers of science, man's new duties*,³ Jean Bernard set about clarifying the basic ethics of biological research. After analysing the different aspects of the moral consequences of the biological revolution, he refers to the neighbouring areas of science, medicine, philosophy, theology, politics, the economy and the law, and in 1990 he recommended the establishment of ethics committees in

1 F. Mayor, 1988, in F. Villardell (ed.), *Ética y Medicina*, Espasa-Universidad, pp. 180-90.

2 N. Lenoir, 1998, *Respect de la vie et droit du vivant*, in *The ethics of life/L'éthique du vivant*, Paris, UNESCO, pp. 175-211.

3 J. Bernard, 1990, *De la biologie à L'éthique*, Paris, Buchet/Chastel.

all countries on an international scale. The challenges posed by the discovery of the human genome in relation to human rights were discussed with great authority by numerous authors, including Eugene B. Brody himself in 1993.⁴

Anticipation. The thorough knowledge of physical, environmental, cultural, economic, sociological, physiological and pathological phenomena is essential for any ethical approach. The first step consists in obtaining all the knowledge available on a particular subject and identifying those gaps which might require further research. It is therefore essential that the measures, founded on ethical principles that should be adopted by current administrations, involve a very precise and comprehensive consideration which includes the possibility of the point of no return. As a scientist who has been involved for many years with the prevention of infant mental deficiency, I am well aware of the extent to which the potential irreversibility of any process does not, from an ethical point of view, allow us to defer the adoption of corrective measures. If we rely on competent diagnosis and appropriate treatment, why wait to put it into practice? It was this feeling of ethical urgency that inspired me to write, towards the end of the 1980s, a book entitled *Tomorrow is always too late*.⁵ In 1989, I raised the issue of that specific challenge which occurs in all fields of knowledge and politics – that of taking of decisions in time, in order to avoid irreparable negative consequences.

In this same context, aspects relating to the ‘patentability’ of the human genome were discussed at several international science conferences. For example, in 2013, the Supreme Court of the United States established that DNA in nature or on its own is not patentable.⁶ Another aspect of great ethical interest is that of surrogate maternity.⁷ Important issues such as these and bioethics in psychiatry or drug dependency have been addressed at the Bioethics and Law Observatory at the Science Park in Barcelona, directed by Dr María Casado.⁸

Within the ethical-legal implications lies the basic principle of personal heritage within the concept of the heritage of humanity,

4 E.B. Brody, 1993, *Biomedical Technology and Human Rights*, Paris, UNESCO.

5 F. Mayor, 1987, *Mañana siempre es tarde*, Madrid, Espasa-Calpe.

6 J.R. Lacadena, 2013, Patentes de genes humanos, ¿sí o no? Reflexiones en torno a la sentencia del Tribunal Supremo de los Estados Unidos, in *Revista de Derecho y Genoma Humano*, No.38, p.167.

7 E. Corral García, 2013, El derecho a la reproducción humana. ¿Debe permitirse la maternidad subrogada?, in *Revista de Derecho y Genoma Humano*, No.38, p.45.

8 M. Casado, 1996, *Estudios de Bioética y Derecho*, Barcelona, Cedes, see ‘Buscando acuerdos universales’ and *intra* pp. 69-72.

set out in The Universal Declaration on the Human Genome and Human Rights. In the debates on whether or not to permit the use of blastocysts to obtain stem cells, it should be borne in mind that the zygote has the potential to gradually differentiate itself from the embryo, but not the potential to be fully autonomous. It must also be borne in mind that genome expression patterns depend on the molecular environment, and the environmental surroundings of the human being. Therefore, not only the genetic but also the epigenetic characteristics should be considered. Another issue that merits particular bioethical scrutiny is the selection of embryos: *in vitro* fertilization by intracytoplasmic sperm injection. When there are eight cells, two are extracted for genetic study, discarding the oocytes which carry mutations. The 'normal' ones are implanted and an embryo develops which is free from the cancerous genetic pathology. The genetic, pre-implantation diagnosis should be practised only in those cases where it is scientifically justified.

Another very important aspect of today's bioethics is the living will or the regulation of assisted dying. Belgium is currently able to apply euthanasia to minors suffering from an incurable illness. There has to be parental permission as well as the child's awareness of the situation. Seventy-four per cent of the population approve these measures.



UNESCO's role on bioethics. Alterations in genes may be indirect or direct. The former depend on the environment. With the latter, it has to be clarified whether the alteration is with the genes or in the genes. With the genes, it can take place by artificial insemination or *in vitro* fertilization. In experiments where there is manipulation of the genes, there cannot be any alteration of the sequence and, from a purely scientific point of view, there is no objection to those experiments.

In 1991, faced with the exceptional discoveries made in deciphering the language of life, and alarmed by the possible temptation to predetermine the characteristics of human beings, in accordance with the Human Genome Organization, I established the International Bioethics Committee (IBC) to analyse the multiple dimensions of an issue that was giving rise to unprecedented attention the world over.

After five years of work by specialists and government representatives, the Committee drew up the Universal Declaration on the Human Genome and Human Rights, which was unanimously approved by the United Nations General Assembly one year later. Cloning for reproductive purposes is unacceptable from all points

of view, because it removes the individuality that is natural to all human beings. It is an imposition that would lead to a person being designed with the pre-established characteristics of another human being. Let us be clear: it is well-established that there should be no human cloning for reproductive ends, and this is supported by every country in the world along with all scientific communities. UNESCO has already made a great ethical contribution to scientific knowledge, in particular to bioethics. Its pertinent actions in the past bode well for future contributions of the highest importance.



Twentieth anniversary of the International Bioethics Committee

Michèle Stanton-Jean

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Canadian Deputy Minister of Health (1993-1998)
Chair of the UNESCO International Bioethics Committee (2002-2005)
President of the Canadian Commission for UNESCO (2006-2010)
Representative of the Government of Quebec at the Canadian Permanent
Delegation to UNESCO (2011-2014)

In a world where respect for ethical values is often lacking, in a world where economics often take priority over the values of solidarity and the common good, I believe that the fundamental mission of UNESCO, which is to build peace in the minds of men and women, is an essentially ethical mission. One may well think and write that human dignity, solidarity and vulnerability are futile principles that cannot be applied on a universal scale. Nonetheless, whatever our schools of thought – philosophic, legal, historical or sociological, these are values that will enable the development of a science whose applications will respect the men and women who use them, as patients, research subjects, parents or scientists.

Having had the honour of being a member of the IBC for eight years, and, at the time of writing, Chair for three years of the Universal Declaration on Bioethics and Human Rights (UDBHR), I must say that I am convinced UNESCO's bioethical mission remains essential. This experience gave me the opportunity to discuss successive drafts of the Declaration with scientists, civil society and government representatives from several countries around the world. The meetings were occasions to fully understand and get to grips with the challenges

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facing different countries, and to realize the pertinence of UNESCO's work on bioethics.

With the Committee, we produced a Universal Declaration, not universal norms. Because we had understood that norms can be practised only if one respects the cultural contexts in which they are set.¹ Indeed, several Articles of the Declaration take care to underline that all the principles must take into consideration the context of their application.

I should like to add that the work of UNESCO has a duty to examine issues on a theoretical level while maintaining its pragmatic approach, through its action on the ground, its support for the ethics committees in addition to the drafting of instruments as an aid to ethical decision-making. With regard to future challenges, I would mention seven that I feel should inspire the work to be carried out in the years to come.

Multiculturalism. In a world reduced to the scale of a global village, scientists from all over the world are brought together more and more frequently. Funds come from different countries and the ethical regulations vary from one region to another. Combining respect for diversity with the common good will remain an important task given the different religious, cultural and historical currents that exist alongside one another and which impose different perspectives in relation to universal principles. Coming myself from an eminently pluralist society, I have been able to witness the difficulty of drafting legislation, guides and directives, while respecting each community. In Canada, in the Province of Quebec, in order to rule on such issues, they used what is termed 'reasonable accommodations'. I think that there we have a way of confronting future challenges by avoiding a complete cultural relativism, which risks weakening our capacity for effective action.

Power-sharing. Bioethics must continue to include all citizens in its thinking. That is why, in the UDBHR, countries are invited to set up ethics committees which will consult with citizens, thereby avoiding all the power being concentrated in the hands of the medical profession and decision-makers. The sharing of power includes education and in-house training which will allow citizens, scientists and decision-makers to understand the challenges linked to new developments and scientific applications.

1 See Article 26 of the Declaration: Interrelation and complementarity of the principles: This Declaration is to be understood as a whole and the principles are to be understood as complementary and interrelated. Each principle is to be considered in the context of the other principles, as appropriate and relevant in the circumstances.

Bioethics as discipline and praxis. We must work with a broad definition of bioethics that includes the health sciences, but also the natural sciences, and social and human sciences. An approach that does not take social and human sciences into account is an approach that runs the risk of not grasping all the dimensions of the issues linked to current developments in bioethics (psychology, economy, demography, etc.). Although calls for multidisciplinary and transdisciplinarity are included in all reflections on bioethics, we are still wide of the mark.

Community disasters. Since bioethics has traditionally concerned itself with individuals, it is as yet difficult to examine the different questions with at the level of population. The emergence of infectious diseases like AIDS and the H1N1 virus along with the possibility of bio-terrorism and the creation of mega data banks, throw up many challenges to the ways of managing public health and the common good. Policies and practices that limit individual freedom and which may perhaps have an influence on consent, must be adopted; it is essential to look into these matters.

Questions linked to the end of life. Passive and active euthanasia, palliative care, organ transplants, etc. are on the agendas of several countries and form part of the allocation of health resources and of the use of new technologies. Work must continue on these eminently important issues.

New technologies. New technologies have already enabled, and will continue to enable, advances that can reduce the impact of several illnesses on longevity and a healthy life, such as Alzheimer's, Parkinson's, neurological diseases, etc. Data from the data banks could enable an improved targeting of populations at risk. Genetic diagnostics can enable many illnesses to be detected. But all these applications raise other fundamental questions such as, *inter alia*, access to health care, discrimination, protection of private life and the right to know or not to know.

Globalization. Finally, all these challenges include an aspect of global justice. How will the rich countries accept sharing all these scientific advances with less fortunate countries, and how will researchers take into consideration the researchers from countries with less wealthy infrastructures and publishing capacities? Article 15 of the Declaration on the sharing of benefits should be examined in depth in order to specify understanding and possible applications.

These issues show us the magnitude of the challenges that UNESCO's work on bioethics will face in the years to come. It is essential that decision-makers take an interest. At UNESCO, the protection and safeguarding of tangible and intangible heritage interests all Member States. But what is the situation with regard to the interest taken in our epigenetic and genetic heritage, currently subjects of discovery and important application? How can the instrumentalization of human nature be avoided? How can we benefit from the best and avoid the worst? How can we universally apply the principle of the common good? These are the questions facing the Bioethics Programme of UNESCO.²



2 See on this subject: M. Stanton-Jean, *The Universal Declaration on Bioethics and Human Rights: A view of the common good in a world context of plurality and cultural diversity*. <http://www.bnds.fr/>

The imperative of sharing

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Chair of the International Bioethics Committee of UNESCO

The Universal Declaration on Bioethics and Human Rights (UDBHR) of 2005 epitomizes the idea of global bioethics developed by UNESCO over these last two decades: bioethics and human rights. The link appears obvious, when considering the mission of an international agency whose purpose is precisely 'to further universal respect for justice, for the rule of law and for human rights and fundamental freedoms'¹ and thereby contribute to building peace in the minds of women and men throughout the world. However, one could easily maintain that this approach is neither a foregone conclusion nor necessarily the most promising.

The commitment to address 'ethical issues related to medicine, life sciences and associated technologies as applied to human beings'² is not the only way to understand the nature of bioethics. The 'bridge to the future' that Van Rensselaer Potter wished for in his pioneering book of 1971 – as the most striking example – was conceived to reconnect humankind and scientific knowledge with the world around us and life in general. The text was dedicated to Aldo Leopold, who advocated an 'earth ethic' which applied equally to animals, plants, water and even land, to the boundaries of what human beings consider their 'community'. It is true that the Declaration includes among its principles the protection of the environment, the biosphere and biodiversity. Nevertheless, the focus remains on human beings and it is because of the 'interconnection' between them and other forms of life that these

The 'bridge to the future' (Potter)... was conceived to reconnect humankind and scientific knowledge with the world around us and the realm of life as a whole

1 UNESCO Constitution: <http://portal.unesco.org/en/files/16835/1066818100116nov1945.pdf/16nov1945.pdf>
2 UDBHR, Art. 1.

topics are addressed. It is no coincidence that animal rights, which constitute a crucial issue for bioethics, have never been the specific subject of a report by or advice from the International Bioethics Committee (IBC).



Some flaws in the logic of human rights have also been highlighted from different perspectives: the vagueness of concepts such as human dignity; the lack of effectiveness in aligning social rights with binding obligations, especially at international level; the difficulty of detaching a universal and normative idea of good and justice from the individual experience of what is a ‘good life’, as well as the horizon of the concrete, historical forms of collective life in which they are deeply embedded. Under the pressure of these criticisms, one could even be tempted to say that the time has come to abandon the human rights approach and be satisfied with registering the plurality of philosophies, and harmonizing them as much as possible. I think there are at least three sound reasons not to do that.

The first is that human rights provided the bedrock for a decisive enlargement of the bioethics agenda. This development was anticipated in the 2003 IBC Report on the Possibility of Elaborating a Universal Instrument on Bioethics³. Bioethics is fuelled by the unprecedented pace of scientific progress in biomedical and other sciences, which triggers new ethical questions that were previously simply inconceivable, going far beyond the well-known dilemmas relating to the beginning and the end of human life. This self-evident observation goes hand-in-hand with the clarification that bioethics should deal with all ‘the persistent and critical conditions of human beings all over the world and the ethical and legal reflections on birth, child exploitation, gender equality, equality between different human populations, access to cures, disease prevention (...)’⁴. Measures were taken to place bioethics at the very crossroads of all the social and possibly political determinants of health and development: according to Article 14 of the UDBHR, access to quality health care is key, together with access to adequate nutrition and water, the improvement of living conditions and the environment, the elimination of the marginalization and exclusion of persons on any basis, and the reduction of poverty and illiteracy. The list of the main issues addressed by the IBC after 2005, with the aim of articulating and boosting the principles of the UDBHR, provides further evidence

3 Paris, UNESCO, 2003. <http://unesdoc.unesco.org/images/0013/001302/130223e.pdf>

4 G. Berlinguer, and L. De Castro, 2003, *Report of the IBC on the Possibility of Elaborating a Universal Instrument on Bioethics*, Paris, UNESCO, p.3. <http://unesdoc.unesco.org/images/0013/001302/130223e.pdf>

of the overarching importance of this broad, holistic approach: the Report on consent was followed by those on the principles of social responsibility and health, respect for vulnerability and personal integrity, non-discrimination and non-stigmatization⁵. By pointing out the need to go beyond the limits of purely medical ethics and to think of bioethics within the context of human and social rights, the IBC has underlined its pivotal role within the framework of the Millennium Development Goals. To dismiss this idea would imply dismissing the crucial contribution that global bioethics can offer to the Post-2015 UN Development Agenda.

The very pattern of universality ought to be reshaped in this perspective. It is true that bioethics, as well as the human rights discourse, is always on the verge of falling either into the trap of hegemony or that of parochialism, two sides of the same coin. It is just as true, however, that the new responsibilities we are called to take on cannot be confined within the limits of the separate narratives of good and justice. The impact of scientific discoveries, technological applications, new kinds of demand and supply of health care, is global, and global answers are therefore required. We must meet the challenge of building bridges when we look at the most pressing issues on the agenda: bioengineering and the uses of genetics on which predictive and personalized medicine depends in order to flourish; stem cell (ESC) research; the donation of human organs, tissue, cells, and gametes; neuroscience; nanotechnology. The work of the IBC is not limited to providing a global forum where different opinions can be voiced, however important this function may be. Standard setting is also a task, in order to provide something more solid than the simple concept of mutual respect. The controversies that are the consequence of growing pluralism, to which we have become more and more accustomed, and which are already present at the domestic level, are likely to appear almost unmanageable on a global scale. However, this is a challenge that must be met. From the outset, UNESCO has not avoided the responsibility of making decisions and setting priorities. Suffice it to recall the Universal Declaration on the Human Genome and Human Rights of 1997, where the possibility of making profit from the human genome was excluded, relying on its well-known definition as ‘the heritage of humanity’. It is true that this obligation was applied only to the human genome taken in its ‘natural state’ and this clarification triggered further legal conflicts of patentability, which remain a subject of lively debate. However,

5 See URL of reports and advice of the IBC: <http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/international-bioethics-committee/reports-and-advice/>

a moral benchmark was established. From a different perspective, the recent Report of the IBC on traditional medicine systems and their ethical implications,⁶ finalized in 2013, is an example of how to manage the conflict of principles, in this case between the right to access quality health care on the one hand, and the respect for cultural diversity and pluralism on the other. This effort to build consensus around solutions and not just questions is the demanding yet unique alternative to meandering vainly between wishful thinking and lip service.

The third and final observation concerns the main goal of global bioethics. Needless to say, bioethics creates a space where specialists, policy-makers and all citizens can reflect on the limits of science and its applications, and on what we should not do, even if we have or could develop the ability to do it. The IBC has pointed out a second key principle: sharing. After twenty years, it is interesting to revisit the address by the then Director-General Federico Mayor to the First Session of the Committee. Scientific progress, which is ‘unquestionably contributing to setting human beings free’,⁷ poses new questions for the future of humanity and the relationship between human beings and nature, including the nature of humanity (the question of limits). At the same time, however, it is exactly because of these advancements – principally in genetics – that we must affirm that ‘knowingly discriminating would be more of a scandal’ and the sharing of knowledge should be considered as ‘one of the greatest priorities of our times’. This is why bioethics ‘is not a luxury’ and therefore not the preserve of a few, but ‘the concern of the entire human community’. This must be understood in the broadest meaning of the term. Scientific progress cannot act as an instrument for reinforcing the shortcomings of inequality. To address the risk, it is not enough to share benefits if they are the result of a top-down charitable strategy. The production of knowledge should become a common endeavour, through the active participation of developing countries in the setting up of agendas, in the establishment of centres and networks of excellence for education, research and clinical practice in these countries, the promotion of an effective knowledge-sharing policy. This kind of sharing is based on the principle of equal dignity for all human beings. It is not about metaphysics. It is about the world we live in.



6 Report of the IBC on traditional medicine systems and their ethical implications, 2013, Paris, UNESCO. <http://unesdoc.unesco.org/images/0021/002174/217457e.pdf>

7 F. Mayor, 1994, Address by the Director General, in *International Bioethics Committee of UNESCO: Proceedings 1994*, Paris, UNESCO, p.64. <http://unesdoc.unesco.org/images/0012/001203/120377mo.pdf>

Rethinking the conception of human nature

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There are many reasons why it is fitting to state that Human Rights constitute a league table for our times. This acknowledgement does not, of course, imply ignoring or underestimating observations of which they have been the subject. But it is unavoidable that along with the various declarations, commissions, meetings, conferences or other programmes and activities of UNESCO, Human Rights and their implicit values have permeated the whole of society in today's world, with global reach, going beyond Western tradition and probably even further than our times.

In the field of Bioethics in particular, it is this guideline of principles and values that has been able to provide the essential means – ethical, political, social and legal – to confront the extraordinary moral impact of the biosciences and biotechnologies, particularly genomic and neurobiological, brought about by great scientific and technological revolutions. UNESCO's initiatives in relation to Bioethics have been an undisputed success, from the setting up of the International Bioethics Committee to the culmination of The Universal Declaration on Bioethics and Human Rights.

It can be stated that this Declaration stands out above all by its conscious intention to reconcile axiological and legal universality with plurality and cultural diversity. Equally, this proposal carries with it the major challenge of being both

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binding and not binding at the same time; the fact that the norms and duties both are and are not of a binding nature; hence the wording in the conditional (use of 'should'), leaving open the possibility that it is up to the individual State to translate autonomously and specifically the terms of the Declaration into legal or moral norms.

In pointing out these features of UNESCO's achievements over the past twenty years in relation to Bioethics, the aim is to make clear the unquestionable need for such achievements and distinctive elements to be reaffirmed and enriched in the future. And precisely because of new knowledge and powers over life, one can begin to see the particular need for ethical and humanistic criteria which contribute to the survival of humankind itself and its habitat. In this sense, there are two important challenges that stand out for Bioethics in the coming years.



Firstly, the continuous threat of the 'fantasy' of post-man or post-human. That is, the growing power of the techno-sciences gauged by their tempting capacity for euthanasia, in the broadest sense of the term; in their power to mutate individual or collective human nature, whether through genetics or brain cells, by means of the drive to intervene physically and voluntarily in the micro-universe of DNA or the human brain, including that of other living beings, manipulating and altering their natural constitution. This is where science-fiction stops being fantasy, imagination or literature and becomes disturbing reality.

The key lies, in effect, in the potential to penetrate the inner universe of the genetic programme or of human neuronal life, with the aim not to heal injuries or natural defects, but to 'improve' or 'perfect' that given by nature: intelligence, emotions, desires; in sum: our personality. That is to say, the capacity to accentuate some tendencies, cancel out others, to activate or deactivate character traits, to redesign the human personality; in this respect, as we already know, drugs are becoming increasingly significant.

Along with this power of intervention and transmutation comes the power of nanotechnologies, this truly extraordinary new dimension of techno-scientific work that is no longer micro, but nano. But what is this, exactly? Nano particle? Nano scale? Nano structure? Nano world?

UNESCO acknowledges the urgency with which it must analyse in great detail the capabilities of nanotechnologies, with particular emphasis on the ethical aspects. Indeed, so very unusual and magical are the promises, that we think that with such a 'nano world', we are embarking on a new era of civilization. Thus, in the

field of medicine and health in particular, the healing of previously incurable illnesses is being predicted, along with the production of far more effective personalized drugs. In other areas, we might see extraordinary agricultural and food production, and the solution to the problem of the contamination of water, the atmosphere and the soil, among numerous other wonders that contribute as much to life as they do to matter. But the threats and dangers of these all-powerful means are as great as those of nano-biotechnology. It is growing exponentially and, with it, increasing appeals from scientists, technocrats, politicians, industrialists, etc. for the need for ethics and bioethics in all fields.



Secondly, it is essential to deal with and discuss the connection between theory and practice, between the level of the basic sciences and that of their practical application. It must be emphasized that new bio-scientific knowledge is of such a radical, transcendental newness that it is creating critical conditions for some of the most solid foundations of our culture. It calls into question not only the axiological guidelines upheld by ethics and bioethics, but the very certainties upon which Western civilization has been founded for centuries.

Therefore, it is imperative that bioethics confront the theoretical or cognitive issues raised by the discoveries of the new life sciences which are also becoming closer to the new, revolutionary concepts of philosophy and social science. It is essential that ethics and bioethics respond to this crisis of the basic principles in the conception of human nature that the life sciences set out. This should obviously be without detriment to the ongoing task of ensuring – immediately and in a practical manner – that ethical and human rights values prevail where the application of the biosciences, biotechnologies and especially nanotechnologies are concerned.

At this point, it is important to recall Kant's linking of the following questions: What must we do? What can we do? What can we hope for? What is man? It is precisely this last question, relating to ontological foundation, that does not yet appear to have a definite answer, rather the contrary. Since Darwin, the main issue called into question by the new revelations of bioscience has been the traditional conception of human nature. Linked to that have been questions on such facts as the constituent elements and the very definition of what constitutes the human being, such as freedom, dignity, solidarity, spirituality – in short, the singularity of the human condition

Indeed, new advances in the life sciences have shattered the most deeply-rooted convictions and have left their mark on the history of thought, culture, existence, ideas, rights and values, philosophies and morality itself. These are convictions that, ultimately, have been based on the certainty that there exist two worlds and two sides of reality – matter/spirit, body/soul, reason/feeling, physical nature/essential nature. Thus the most diverse dualisms are almost nullified when the biosciences demonstrate unity and continuity of all that is living, governed by deterministic laws. What was called ‘soul’ or ‘spirit’ is not an immaterial or supernatural substance, separated from the biological, physical-chemical nature of corporeal reality. We arrive at the monist conclusion, and with it the reductionist interpretations which maintain that liberty and dignity are illusions or purely ‘folklore’ psychology.

Nonetheless, with their characteristic, rapid development and the maturing of their knowledge, these same biosciences are also opening up new pathways in the understanding of facts, allowing us to overcome reductionist monisms and revealing the possibility, of returning not to dualist conceptions, but instead to a conquest of the spirit, recognizing that it comes from the natural, neuronal nature of the human being itself, just as it is inconceivable without its interrelation with both the natural and the cultural or socio-historical world.

To conclude, it appears indispensable for the bioethics of the future to go further into the ambivalent interpretations and findings of bioethics, and to tackle the key question: what is human nature? For the answer will be the foundation of human rights and values and, from there, of the basic criteria for guiding and leading – both ethically and humanistically – the future practices of the all-powerful technological life sciences.



The need for new ethical perspectives

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The new focus of attention in biomedical research is in great part due to the constant development of molecular biology, the knowledge of the human genome and other derivations (genomic, proteomic) and the use of various new techniques that allow or will allow intervention in living matter at the molecular level.

Today, we are developing new medicines: predictive-preventive medicine, thanks to genetic analyses which allow us to anticipate the first manifestation of an illness before the first symptoms are apparent and, in such a case, to take therapeutic or preventive measures, with the emphasis on genetic intervention; thanks to the knowledge of individual reactions and the genetic characteristics of each person, personalized or individualized medicine will be able to administer drugs that are appropriate for each person, thus being more effective and less aggressive (pharmacogenetics); and regenerative medicine which, in harmony with and thanks to the use of stem cells of varying origin, will be able to reconstruct parts of the body damaged by trauma or degenerative illnesses (Parkinson's, Alzheimer's, diabetes).

All this demands not only an organizational or economic response, but also others, primarily ethical. Only after that will we be able to set out with greater precision the legal treatment needed. Indeed, much of this research which requires such advanced medicine and its later clinical application to human beings, opens up ethical dilemmas, some of which are extremely complex.

Predictive medicine is based, in the first instance, on the knowledge that can be obtained on the health of a person from the analysis of his/her genes, along with the technical possibilities that allow the use of personal information: genetic data. We must remember that the information derived from genetic tests carried out on a particular person present specific characteristics that differentiate this information from other findings:

- ❖ its origin and characteristics do not depend upon the will of the individual (they are passed on by the parents, who have no influence on the characteristics which, in turn, they pass on to their descendants);
- ❖ its base is indestructible, being present in all the cells of the organism while it is alive and even after death;
- ❖ it is permanent and inalterable, except for spontaneous genetic mutation, produced by the action of exogenous agents responsible for some serious pathologies or caused by genetic engineering;
- ❖ it has a predictive ability (pre-symptomatic illnesses), that can indicate whether the person being examined is a carrier, for instance in the case of a patient who does not suffer from the illness but could transmit it to his/her descendants;
- ❖ its singularity and exclusivity (except for identical twins); and
- ❖ its link with the biological family, both vertically (ancestry and descendants) and horizontally, where it can also provide information.



The ethical and legal thinking on individual genetic information indicates that it merits protection similar to that accorded to data relating to health, where it is classified under State legislation as ‘sensitive data’, thereby enjoying special protection. Protection should exist of the strongest kind when we are dealing with genetic data for personal health, regardless of the level of ‘genetic exception’. This status may change in the coming years and the consequences may be of such importance that international bodies like UNESCO may need to intervene to establish the necessary framework of action.

Firstly, I want to talk of the full sequences of the individual human genome, as well as mass partial genome sequencing. Specialists point out that because the cost has been gone down so much, these sequences could very soon be accessible to everyday medical practice. It is understood that mass sequencing constitutes a new form of obtaining personal health data in greater quantity, better quality and more efficiently. This also enables us to obtain more information on the genetic variants of the illness. The complete sequencing of the genome and of the exoma of each individual will facilitate greater knowledge of high-risk deleterious genes and their incidence in future illnesses, through early diagnosis. This, in turn, will strengthen predictive, preventive and personalized medicine.

As has already been suggested, these procedures are not exempt from their own ethical problems. Firstly, a vast amount of sensitive

information will accumulate in hospitals and diagnostic centres, so a decision must be made on how to deal with this. It will be necessary to apply a special seal for its protection from third parties, since there is likely to be an increase in the risk of discriminatory or stigmatized practices. With regard to the transmission of information to those concerned, irrespective of whether this involves complete or partial DNA sequencing, individual or collective, there is clearly a difficulty when it comes to passing 'complete' or 'relevant' information to the person concerned, because it does not seem reasonable to provide 'all' the information obtained. So what should be the criteria for selecting the information to be conveyed? On the other hand, the transmission of unexpected findings, which will increase with complete or mass sequencing, will be especially delicate.

With regard to reproductive medicine, mass DNA sequencing in the unborn (foetus, embryos and *in vitro* embryos) can provide a wealth of information on genetic anomalies that can become apparent after birth or during gestation, such as malformations, pathologies or lifelong predispositions to these. It has been emphasized that this information could lead to an extension of the practice of abortion. Probably, the widespread norm should be maintained, which is that there must be a specific, prior indication before any pre-implantation or pre-natal genetic analysis is decided upon by a genetic consultant, not blindly, as with mass sequencing.

As a brief, summary reflection on this point, we could conclude that mass sequencing has to submit to the principles of proportionality, pertinence and quality. Genetic analyses must maintain links with a committee on genetics, in order to be more than mere consumer practice. In some cases, this will lead to the restriction of its practice, of access and use of the information obtained from each individual, or of its transmission to the latter.



The other issue putting great pressure on access to genetic data and biological samples of human origin, is connected with the globalization of biomedical research in many projects shared by groups of scientists in different countries. In order for these macro

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projects to be successful, there is a need to ensure a rapid, full flow of information among the researchers. Nevertheless, we find ourselves with a paradox: researchers are subject to laws on the protection of data of a personal nature in their respective countries, in this case, relating to health; in some cases they come up against the problem that the levels of legal protection differ very widely from one country to another, which makes exchange difficult. And, on the other hand, there is no international regulation on this linking issue, without prejudice to UNESCO's International Declaration on Human Genetic Data.

While researchers have complied with the rules on genetic information and anonymous biological samples, no limit has been set. Since the starting point was the reversible transfer of decoded data, so that researchers receiving the findings could not automatically identify the owner, but could identify them if it were deemed necessary to review their clinical history or for another motive, the issue of informed consent had to be 'reinterpreted', particularly with respect to the extent of data transfer to third parties. In principle, this data would be of a personal nature ('identifiable persons'), but it is the researcher transferring the data who takes on the duty of confidentiality regarding the transmission procedure, therefore the researchers who receive the data do not have access to any data of a personal nature. Since it is essential for their research, some scientists are asking for the data and samples to be transferred with the full identification of their owners, without giving any guarantees of confidentiality or privacy, thereby prioritizing research interests over that of the autonomy of the subject concerned.

As can be verified, these issues require urgent regulation and an appropriate ethical foundation, since some extreme positions may be to the detriment of some individual rights; if science and society do not show any interest in these subjects, such interference may become justified.



In search of universal agreements

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Over recent years, UNESCO, through its Bioethics Section, has accomplished a major task both with the programmes it has designed and developed and through its contribution to found and disseminate a concept of bioethics rooted in respect and the promotion of internationally recognized human rights; the moral, legal minimum that universally links us and a fitting standard for resolving conflicts in our globalized, plural world. As UNESCO states, bioethics concerns everyone and building it has to be a shared task. In a world that is going through fundamental change and transformation, the mission of ‘critical conscience’ that UNESCO has developed since its creation takes on an even greater importance.

A number of UNESCO’s activities are developed through the work of UNESCO Chairs and the UNITWIN Networks, which carry out their work in accordance with the guidelines laid down by UNESCO’s programmes. Speaking personally, I feel honoured to hold the UNESCO Chair in Bioethics at the University of Barcelona,¹ whose work is developed along guidelines that conform totally with those of UNESCO. It supports the policies guiding the activity of the Bioethics Section with which the Chair works in close cooperation. This shows the importance of its training and education work in bioethics which is carried out specifically for members of the ethics committees. In the same way, the work undertaken is aimed at the general public, and becomes a means of democratization and involvement in decision-making on subjects of common concern in the field of ethical issues relating to medicine, the life sciences and associated applied technologies. This task is necessary in order to be able to conduct informed social debate while taking into account

1 The UNESCO Chair in Bioethics at the University of Barcelona was established in 2007 with the support of the research centre ‘Observatory of Bioethics and Law’ in the fields of research, teaching and the transfer of knowledge. The Chair has its own Internet portal on the website www.bioeticayderecho.ub.edu. It is part of the group of nine UNESCO Chairs in Bioethics established in the world, and the only one in Spain.

social, legal and environmental aspects. Assistance Programmes for committees and ethics training are contributions that should especially be highlighted since their effects are widespread; not only with regard to the setting up of committees in countries where previously none existed, but these assistance programmes are also used for training members of established or newly-created committees.



Among the extensive responsibilities of UNESCO's Bioethics Section, whose twentieth anniversary we are celebrating, should be highlighted the importance of the support and encouragement it has provided, along with the International Bioethics Committee and the Intergovernmental Bioethics Committee, for the drafting and subsequent approval of the three Universal Declarations which constitute the basic *corpus* of the norms on bioethics of universal reach. In accordance with its Constitution, UNESCO plays a distinguished role in the definition of universal principles founded on common ethical values, which guide scientific advances, biotechnological development and social transformations. Based on the established principles set out in The Universal Declaration on the Human Genome and Human Rights, the International Declaration on Human Genetic Data and the Universal Declaration on Bioethics and Human Rights (UDBHR), which constitute the core principles guiding our work in all aspects of bioethics, we can establish a global, plural dialogue which centres around the issues under discussion.

In this regard, one of the most significant contributions of the UDBHR is that its objective is to draft common universal principles for resolving bioethical conflicts. One most interesting aspect is that it states its task is to provide solutions and, indeed, it does provide them. Thus, it responds to the universalism-particularism polemic in a unique manner, setting out its key proposal in Article 2 (a): 'to provide a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics', which, to my understanding, constitutes the authentic core of the Declaration and takes the view that it is both possible and desirable to manage to formulate some principles of good conduct that are universally acceptable. The impression of such a concept being based on the theory of natural law fades before the nature of the agreement brought by the Declaration, both through its drafting procedures and the minimum levels it sets for reaching possible compromise among 'the members of the human family'. The aim of Article 2 (c) is also fundamental: 'to promote respect for human dignity and protect human rights, by

ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law'. By specifying that human rights are recognized in international law, it allows for a common concept of human dignity, understanding it to be a condition in order to live life to the full and to co-exist with those who are different.

Since it was first formed, UNESCO has been confronting the problem of how to achieve compatibility with opposing cultural thinking: emancipation and integration, universality and multiculturalism. The diversity of the two approaches, the point of view of liberation (for the universality of human rights) and that of integration into specific circles (family, ethnic groups, corporations, etc.), is clear when they focus on human rights and human dignity, since it is difficult to know whether both approaches will continue to be irreconcilable. With the UDBHR, UNESCO adopts a position that seeks universal agreement on ethical, social and legal-political aspects which are the core of bioethics. The necessary response to ethical issues raised by advances in science and technology (Preamble of the Declaration), is based upon the ability of human beings to think and their moral sense to perceive injustice and assume responsibility for it according to cooperative criteria and ethical principles of a universal nature that the international community should establish, taking into account respect for human dignity and human rights. The General Conference, on proclaiming the principles set out in the UDBHR, which it adopted, stressed the need to strengthen international cooperation in the field of bioethics, taking into account the specific needs of developing countries, indigenous communities and vulnerable populations.

All the Articles put forward objectives following an order that begins with the individual person and his/her autonomy and relationship with other human beings and communities, and then broadens to include all living beings and the environment. In this

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way, the UDBHR sets its objectives adopting individual and collective views, going from autonomy to justice, and from solidarity to social responsibility. This constitutes innovative objectives that make clear the scope of the aims to which they are committed. Although the content of each of the principles is ‘minimal’, the progress implied is clearly set out in the Declaration and by the use of points based on bioethical conflict resolution.



From there on, the core of the discussion relating to current bioethics is centred on the step ‘from principles to rules’ and given that the Declaration provides us with common principles, it is a matter of establishing rules, binding legal norms, that are effective and reinforced with sanctions. In order to accomplish this, it must be determined which principles are applicable in each specific case, their scale of importance decided and conflict resolution criteria established before reaching a decision. The principles recognized in the UDBHR share a common base and level of support to attain a global bioethics which evolves, is flexible and capable of helping solve bioethical problems as well as promoting equality and respect for human rights. This is the challenge facing UNESCO’s Bioethics Section.



Twenty years fostering convergence and cooperation in global ethics

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A silent and invisible power is present when people from different cultural backgrounds and belief systems gather in an environment of mutual respect to search for what they have in common. Differences among peoples are a reality, but none of them should weaken the universal conviction of the need for and the value of ‘unrestricted pursuit of objective truth and the free exchange of ideas and knowledge’. In modern and contemporary society this assertion could be easily labeled as intellectual fundamentalism. Few would suspect that this statement comes from the Preamble of the Constitution of UNESCO, adopted in London on November 16, 1945. As an international law in force, this instrument should not be ignored or misinterpreted. Rather, it is crucial to read it often, to keep it in mind, and to consider it while constructing public policies and making ethical decisions. It should also serve as an important point of reference in our university endeavours.

Hence, neither contemporary relativism nor individualistic subjectivism satisfactorily accomplish the task of furthering universal respect for justice as indicated in Article 1 of the UNESCO constitution. In the field of bioethics, ‘[...] the importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms’¹. In other words, cultural diversity and pluralism are not ultimate considerations for ethics and justice. Respect for diversity and pluralism does not take precedence

1 UNESCO Universal Declaration on Bioethics and Human Rights, adopted by acclamation on October 19, 2005.

over the principles that must serve as a starting point, namely the recognition, protection and upholding of everyone's human rights.

This is, in my opinion what the UNESCO Bioethics Programme has been fostering and carrying out in the last twenty years with dedication and engagement. Through its commitment to promoting reflection on the social responsibilities of scientists, its diverse institutional actions have illuminated the resolution of emerging bioethical issues in the field of life sciences and medicine. UNESCO's leadership in educational, political and cultural initiatives is well known among experts: from its three Universal Declarations (establishing norms, principles and guidelines for national policy-makers, individuals and other stakeholders) to the establishment of UNESCO Chairs and specialized networks in bioethics; from the support for the establishment of national bioethics committees in developing countries to the educational programmes and publications, which are extremely helpful for teachers involved in bioethical training.



On the one hand, the globalization of health care and medical research runs the risk of discrimination, exploitation and injustice that can be prejudicial for poor or developing countries. UNESCO's Bioethics Programme has been especially sensitive about these challenges, broadening the vision of bioethics and focusing on social justice issues. On the other hand, its multicultural approach allows it to clarify bioethical issues by a more communitarian and social approach that enhances the centrality of the person in his or her individual and social dimension. This anthropological approach, open to diversity and our conviction of universal dignity and human rights, will enhance UNESCO's mission to foster convergence and cooperation in global ethics over the next twenty years.

The more we assimilate knowledge, the more difficult it is to communicate, share and persuade others of our ideas, convictions and beliefs, especially when confrontation is judged as the only way to reach unity and peace. Creating an illusion of uniformity can wrongly be considered necessary to govern peoples; in a misguided concern for harmony in a globalized and multicultural world, disdain for the act of dissent can emerge. To learn from peoples from other cultures, intellectual integrity and a firm desire for openness are required. I am convinced that meeting experts, State representatives and diverse leaders illuminates our perception and knowledge of humankind.

It is easier to remain in the comfort zone of our field of knowledge and not be challenged in our intellectual, moral and religious convictions. But this is neither intellectually truthful nor

ethically sound. The UNESCO Constitution declares: ‘...that the wide diffusion of culture, and the education of humanity for justice and liberty and peace are indispensable to the dignity of man and constitute a sacred duty which all the nations must fulfill in a spirit of mutual assistance and concern’. This is not only a political responsibility to be considered by nations and states, but also a personal duty we all should undertake as a moral commitment. UNESCO has been deeply involved in this endeavour.

Differences could be considered as a deterrent to working together in a spirit of respect. Diversity creates fear everywhere. Our ignorance about what different countries and cultures think and believe often builds walls of suspicion and mistrust. Different beliefs, different ideas, different philosophies, different languages, different colours, different states: too many differences for some people’s thoughts and fears to handle.

But a different and more positive way of thinking is possible. Building intellectual and moral bridges is a moral imperative nowadays. It demands a personal and communitarian effort to overcome ignorance of neighbours near and far, since ‘...ignorance of each other’s ways and lives has been a common cause, throughout the history of mankind, of that suspicion and mistrust between the peoples of the world through which their differences have all too often broken into war’². A spirit of mutual understanding and friendly dialogue is not only possible, it is a moral obligation that helps to build unity where it is most needed for the sake of justice and ethics.

Some people believe that religious convictions are an obstacle to scientific and technological progress, and therefore believers – though intellectually competent – should be considered in a lesser light, since they could stop or delay new discoveries or therapies due to moral reflections and convictions they bring into consideration. From this unfair assumption emerge fear and a subtle discrimination that must be avoided at all costs. Our diverse and globalized world needs to assume the risk of engaging with each other through sincere intellectual efforts. Virtue can spur us on to overcome what divides us to our detriment.

A spirit of mutual understanding and friendly dialogue is not only possible, it is a moral obligation that helps to build unity where it is most needed for the sake of justice and ethics

2 Preamble of the UNESCO Constitution, 16 November 1945.

In the field of bioethics, the endeavour of bringing together leaders and state representatives from diverse cultural and religious traditions might appear a vain, even useless, effort. Is it possible to find convergence, not only at the level of principles, but also when we suggest establishing valid guidelines for a globalized world in which opposing views appear almost impossible to reconcile?

The core of our mission in the UNESCO Chair in Bioethics and Human Rights consists in creating a forum of diverse bioethics leaders, delivering a common framework to guide the application of bioethical principles, and informing and influencing ethical, legal and public opinions, decisions and actions relative to medicine, life sciences, and human rights and responsibilities. When I reflect upon the work that the UNESCO Bioethics Programme has been carrying out in the last twenty years, I am happy to see the same lively spirit of cooperation to improve progress in bioethics, and by doing so, to contribute to some extent to the achievement of the Millennium Development Goals related to health, environmental sustainability and basic education.



Among the expected developments for the next twenty years of UNESCO Bioethics Programme, I would suggest, on the one hand, the exploration of the possibility of negotiating an international treaty in bioethics and human rights based on the principles set out in the Universal Declaration on Bioethics and Human Rights. This would be the natural way of transforming the universal principles from soft law into hard law – similarly to what happened with the Universal Declaration of Human Rights (1948) when transformed into hard law by means of the International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1966).

On the other hand, I think the UNESCO Bioethics Programme could share best practices and know-how about international cooperation in global ethics within intergovernmental organizations and other international organizations and forums dealing with human rights at a regional level. This endeavour would entail suggesting, supporting and promoting the creation of specific departments or divisions of bioethics within the most relevant forums, such as the Organization of American States, the African Union and the Arab League. UNESCO knows very well how to do this, since it is something that has already been established in the Council of Europe as well as in the European Union. In the next twenty years that would be a precious contribution to the challenging endeavour of global bioethics.



Global bioethics and global intellectual property law

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The foundation of the United Nations, in terms of the Charter of 1945, was based on aspirations of achieving international peace and security; economic equity; and development and universal human rights. As a species, we have not always succeeded in securing these goals. But UNESCO has made significant contributions. During my service on the International Bioethics Committee (IBC), two international instruments were adopted which I must mention. The first was the Universal Declaration of the Human Genome and Human Rights (adopted by the General Conference in 1999)¹. In its provisions, specific to the genome, UNESCO signalled its concern that progress in scientific research should not benefit only the wealthy, but be available for all humanity.²

UNESCO's Universal Declarations. Substantially coinciding with the work of the IBC on the foregoing two Universal Declarations, was important and innovative work happening elsewhere in the United Nations system. In the early 1980s, a deadly new virus became known, namely the Human Immunodeficiency Virus (HIV). In its final stages, this virus would normally cause the death of those infected. At first, there was no effective treatment; and no preventative vaccine. There is still no cure and no vaccine. However, in the 1990s, by the genius of science, treatment with a triple combination of antiretroviral drugs (ARVs) was shown to have

1 UNESCO, General Conference, Resolution 29C/Res16, reprinted in Records of the General Conference, UNESCO, 29th Sess., 29 C/Resolution 19, at 41 (1997), adopted by the UN General Assembly, G.A. Res 152, UN GAOR 53rd Session: UNDOC A/Res/53/152 (1999).

2 See articles 4, 11 and 12 of the Universal Declaration of the Human Genome and Human Rights; and section C, D and F, articles 14.1, 14.2 A, and 15.1 of the Universal Declaration on Bioethics and Human Rights (UNESCO General Conference, adopted on 19 October 2005, 33rd session GCFCE).

lifesaving effect. People with access to these ARVs began to feel better and to return to work. Moreover, the medicines had the highly beneficial effect of reducing the viral load in such people and thereby reducing their capacity to infect others by passing on the virus. In the early years, the ARVs were only effectively available to wealthy patients or those living in developed countries with strong systems of universal public health. They were not available in developing countries, although the centre of the epidemic was in Sub Saharan Africa and other poorer regions of the world where thirty million people became infected and many died. It was at this time that the joint United Nations Programme to combat the spread of HIV (UNAIDS) and the World Health Organization (WHO) resolved, exceptionally, to mobilize world efforts to provide ARVs to people everywhere.

By acting in this way, these UN agencies were conforming to the ethical principles inherent in the Charter and endorsed by UNESCO

Given that both the attainment of essential physical and mental health and the protection of interests from scientific inventiveness are recognized in the same international statements of human rights, the task is presented to balance and reconcile the competing claims of these rights

and the IBC. Access to the highest attainable standard of health should not depend upon the chance event of location or birthplace. It should be a birthright of every human being, in accordance with the principles expressed in the Universal Declaration of Human Rights (Art. 25.1) and the International Covenant on Economic Social and Cultural Rights (Art. 12). A great effort was mobilized to provide antiretroviral drugs to people living in developing countries who would otherwise have died. At first, the objective was to ensure that 5 million people (of the estimated 30 million who had been infected with HIV) would have access to the ARVs by 2005. Then, bolder goals were set to provide access to 10 million who would benefit from the drugs. As scientific knowledge advanced, it

became clear that 15 million patients would benefit from access to the ARVs. However, by this stage a significant challenge loomed in the path of such access. It was a challenge that manifested itself in the form of international intellectual property law (specifically the law of patents in respect of pharmaceutical drugs).

Rewarding inventiveness. Intellectual property (IP) law is an ancient form of protection for those who develop new inventions. Because inventiveness is universal, international treaties were developed in the nineteenth and twentieth centuries to promote patents and to encourage uniformity between the domestic laws of nations. The chief system relevant to patenting pharmaceutical products is now expressed in the Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS), signed in 1994. TRIPS is administered by the World Trade Organization (WTO), a non-UN body to which most countries of the world have joined up. TRIPS introduced IP protection at a breadth never seen previously at the multilateral level. In exchange for the public revelation of the secrets of the invention, the inventor is granted a legal monopoly to sell and profit from the invention for a period of time. Under TRIPS, this period is a minimum of twenty years. The aim is to reward the inventor and to promote research and development. IP and patent law are not incompatible with universal human rights law, as they are recognized in Art. 27.2 of the Universal Declaration of Human Rights. Likewise, such rights are recognized in the International Covenant on Economic, Social and Cultural Rights³. Given that both the attainment of essential physical and mental health and the protection of interests from scientific inventiveness are recognized in the same international statements of human rights, the task is presented to balance and reconcile the competing claims of these rights.

Unfortunately, this reconciliation has not been well achieved in the international community. In part, this is because the international treaties on IP law largely predated the Charter of the United Nations and the human rights treaties that followed it after 1945. In part, the reconciliation has not occurred because human rights treaties are administered by UN agencies, and international IP law has been administered in recent years by the WTO, a non-UN agency. Human rights law has developed along lines of fundamental principles. IP and patent law has developed along lines of economic interest, international, national and corporate profitability and market forces.

The need for reconciliation is rendered urgent in the case of the HIV/AIDS epidemic. This is because the initial drugs that formed the cocktail of ARVs are now demonstrating inefficiencies and unwanted side effects. Those drugs have substantially been available in cheap generic copies that ensure the necessary pharmaceuticals can be provided to poor people in poor countries at a tiny fraction

3 See article 27.2, Universal Declaration of Human Rights. Cf. Art 15.1 A and B, International Covenant on Economic, Social and Cultural Rights.

of their original patented cost. But with the so-called second line and third line therapies of pharmaceuticals, the cost of new ARVs rises exponentially. The costs become prohibitive for national governments and international bodies such as the Global Fund. The real prospect begins to loom that effective ARVs will not be available in developing countries. Moreover, some patients, already receiving such drugs, may not be able to continue their treatment. The result, potentially, will be a return to the death of millions; which is an unthinkable but not impossible prospect. It arises from the want of reconciliation of conflicting branches of international law.

What can be done? To address the issue of what can be done by the international community to achieve the essential reconciliation, a number of global bodies have addressed their attention. In 2001, the UN Commission on Human Rights has authorized a study by the High Commissioner for Human Rights who issued a report calling for action.⁴ In 2012, the Global Commission on HIV and the Law, established by UNDP, delivered a report *Risks, Rights and Health*.⁵ Other international bodies drew attention to the urgent, approaching predicament.⁶ I have served on a number of these bodies.⁷ The challenge is an extremely urgent one. The answers cannot be delayed. In October 2013, the heads of UNDP, UNAIDS and OHCHR wrote to the Secretary-General requesting action on a UNDP Commission recommendation.⁸ So far, a high-level expert inquiry has not been established, and meantime a number of unfortunate developments have been happening within and under the impetus of WTO. These have included the initiation of many so-called Free Trade agreements which have contained provisions which have removed the possibilities of such exceptions and qualifications on protection of the right to health as exists thereunder. Negotiation of multilateral treaties such as the Transpacific Partnership and the proposal of international treaties such as the Anti-Counterfeiting Trade Agreement (ACTA) have proceeded. Far from producing the burden of IP and patent law on pharmaceuticals for poor countries,

4 United Nations Economic and Social Council, Commission on Human Rights, report of the High Commissioner for Human Rights, *The Impact of the Agreement on Trade-Related Aspects of Intellectual Property Rights*, E/CN.4/sub.2/2001/13 (2001).

5 UNDP report, New York, 2012.

6 See e.g. Commonwealth Secretariat, report of the Eminent Persons Group, 2011, *A Commonwealth of the People: Time for Urgent Reform*, London, p.98 (*Advocacy on HIV/AIDS: A Commonwealth Health and Economic Development Priority*).

7 On UNDP Commission; Comsec Group; and UNAIDS/Lancet Commission, *Defeating AIDS – Advancing Global Health*.

8 On 'A neutral, high-level body to review and assess proposals and recommend a new intellectual property regime for pharmaceutical products ...'

these treaties have sought to reduce capacity to use generic drugs so as to reduce the cost of medicines in the developing world.

Time for bioethical action. The issues referred to in this note are critical issues of bioethics. Literally, they concern matters of life and death and of human welfare, happiness and survival for millions of human beings. It must be hoped that the international community will respond to the recommendations now before the UN Secretary-General and that the response will conform to the fundamental principles of bioethics stated in the UNESCO Universal declarations.



PART THREE

Evidence, Context and Specificity

Pluralism and protection of vulnerable individuals and groups

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The accomplishments of the International Bioethics Committee (IBC) are the outcome of UNESCO's overall commitment to bioethics and human rights issues. Twenty years after the IBC came into being, UNESCO stands as a key protagonist on the world stage with regard to bioethics issues, both at the level of Member States and that of international governance, because UNESCO has finally managed to place bioethics issues on the United Nations agenda. Approaching bioethics as both discipline and praxis, the IBC and UNESCO have worked for normative action and at the same time, by capacity-building activities in Member States. By doing this, the Bioethics Programme aims to establish a bridge between decision-makers, legislators and researchers in science and technology. And in parallel, because of its concern for raising awareness, this Programme encourages debate between scientists and decision-makers, which can then spread out to their societies.



This leadership position came about thanks to three accomplishments. Firstly, because of the three renowned Declarations, the outcome of consultations between international specialists and bioethics proponents, independent IBC experts, members of the Intergovernmental Bioethics Committee (IGBC) and governmental experts, in addition to other organizations of the United Nations system concerned with bioethics, notably the World Health Organization (WHO). Today, these accomplishments constitute an international framework that is both legal and moral, involving all Member States. The various reports and recommendations complete and clarify this normative work by providing information about practices and regulations, both at national and international level.

UNESCO's Bioethics Programme is the second accomplishment, notably through the help it has given to the bioethics committees by fostering and accompanying the training of bioethics committees in several developing countries. With regard to the section on ethics education, the Programme has built the database of the Global Ethics Observatory (GEObs) and designed a training module in bioethics for medical students (the basic bioethics course).

Thirdly, there is the creation of the United Nations Inter-Agency Committee on Bioethics (UNIACB) to coordinate action within the UN system. One of the common, determining characteristics of the success of all these activities is the multidisciplinary, pluralistic approach that aims to link the universal with the individual, by seeking consensus when possible, and when that seems impossible or requires simplification, combining their efforts to present the differing arguments in such a way that they can be understood in their totality by everyone. I should like to underline that I found this to be one of the strengths of the IBC when I took part in their deliberations. The interaction with other members of the Committee – their diverse origins, their training, their cultures and experiences – was an edifying experience and a turning-point for me in my

... the multidisciplinary, pluralistic approach that aims to link the universal with the individual, by seeking consensus when possible, and when that seems impossible or requires simplification, combining their efforts to present the differing arguments in such a way that they can be understood in their totality by everyone

approach to bioethics issues, and from there to the ethics of debate. I can affirm that the IBC was already a school of pluralism, before 'pluralistic debate' was inscribed in Article 12 of the Universal Declaration on Bioethics and Human Rights (UDBHR).

Among the examples of this pluralistic approach, I would mention the report on stem cells (2001)¹ and also the report on pre-implantation genetic diagnosis (2003),² when the ethics of our discussion involved listening and a kindly, patient debate, respectful of the varying opinions, which allowed us to arrive at a consensus

1 A. McCall Smith and M. Revel, 2001, The use of embryonic stem cells in therapeutic research, in *IBC Report on the Ethical Aspects of Human Embryonic Stem Cell Research*, Paris, UNESCO. <http://unesdoc.unesco.org/images/0013/001322/132287e.pdf>

2 H. Galjaard, 2003, *IBC Report on pre-implantation genetic diagnosis and germ-line interventions*. Paris, UNESCO. <http://unesdoc.unesco.org/images/0013/001302/130248e.pdf>

and a compromise acceptable to the members of the IBC, then later approved by the UNESCO Member States through the IGBC. I conclude from this experience that if this kind of ethical dialogue were to prevail during discussions on the great or small issues that humanity raises, then there would be far fewer conflicts and wars; it is this pluralistic approach and pluralistic debate which help to form respect for cultural diversity as set out in Article 12 of the UDBHR.



On the organizational front, in order to optimize resources, and to avoid duplication and overlapping of prerogatives, it is important to review coordination among the different UNESCO bodies (IBC, IGBC, World Commission on the Ethics of Scientific Knowledge and Technology COMEST), together with the other Agencies of the United Nations system, notably WHO and the United Nations Inter-Agency Committee on Bioethics (UNIACB). With regard to the questions and priority actions, I agree with the Recommendations of the twentieth session of the IBC which should constitute the road map for the years ahead. In particular, I would insist on the request always to connect bioethics issues with human rights, notably respect for human dignity, justice and equality, which are at the heart of UNESCO's mission in its capacity as 'ethical conscience of the United Nations'.

I should also especially like to underline the risks taken by vulnerable groups and individuals. It is essential that UNESCO, together with the other relevant Agencies of the UN system, strengthen their watch so that scientific and technological practice does not exploit or exacerbate those vulnerabilities. As the IBC stressed at its last session, the ethics of governance at technological-scientific level is at the heart of the problem of the protection of vulnerable individuals and groups. Corruption in all its forms and at all levels constitutes the crux of the problem, which like a cancer, invades all the organs of the human family and prevents equitable societies from emerging and enjoying lasting development. One of the issues that is ever present because of corruption is medical fraud and counterfeit medication. These concern 10% of all medication in circulation around the world, but represent less than 1% in industrialized countries as opposed to 20-30% of the market in other regions, like South America, Asia and particularly Africa.³ Trade in counterfeit medication is more lucrative than the drugs market and, according to WHO, will reach the figure of US\$75 billion in 2010.⁴ Here, we are at the heart of the ethics of governance both

3 World Health Organization: <http://www.who.int/mediacentre/factsheets/fs275/eng/>

4 World Health Organization: <http://www.who.int/mediacentre/news/releases/2006/pr09/eng/>

at global and local level, and of the following equation: corruption plus poverty equal worsening of vulnerabilities. It comes down to the fact that this market targets and exploits the vulnerability of poor populations who have no financial access to medication produced in accordance with international norms of quality and safety.

To promote, protect and strengthen human rights in and through the advances of science and technology means completing the work on Article 8 of the UDBHR, given the growing importance of the risk of exploitation of those in vulnerable situations: how to protect vulnerable individuals and groups given the ever greater and varying risks of human trafficking at international level (the trafficking of human organs and tissue, surrogacy)? Where is the dividing line between altruism and exploitation of vulnerability? Women are still vulnerable in many regions of the world and surrogacy adds an additional risk to the merchandising of their bodies. Thus there can be women in situations of vulnerability and extreme poverty who, through necessity, and because of a lack of alternative may 'loan' their wombs.

Thus, the work of reflection and of recommendations on the implementation and promotion of the principles of the UDBHR needs to be continued, notably Article 12: how to promote intercultural dialogue that is respectful of specificities and the universal principles of bioethics and human rights?

Finally, the issue of the migration of health professionals is very worrying. In 2006, WHO estimated the lack of health personnel at global level to be more than 4.3 million workers. Low-income countries are particularly affected, and among the 57 countries where the shortage is deemed critical, 36 were countries in sub-Saharan Africa.⁵ This problem, which in fact is another form of human trafficking to the detriment of the principles of justice, responsibility and solidarity, should be raised and recommendations should be drawn up and proposed.

With regard to practical action, this should focus primarily on developing countries: to continue the promotion and support for national committees with the involvement and commitment of governments of the countries concerned in order to ensure the committees' continuance and independence, and to promote and support teaching and education in bioethics for all actors and decision-makers on health and research. That could be a barometer for the bioethics achievements of UNESCO and the other Agencies of the UN system.



5 OECD Observer, 2010, *The international migration of health personnel. Improving international cooperation to face the global crisis*. Paris, OECD. <http://www.oecd.org/els/health-systems/44786070.pdf>

Bioethics in the twenty-first century: a view from the South

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Bioethics as a multidisciplinary, interdisciplinary subject first came onto the scene in the 1970s with relatively moderate perspectives to provide support for medical practice, which in those days was calling for a strengthening of their ethical foundation. Various concerns were raised at the time, partly because of the tremendous advances in life sciences and partly because of the awareness of the abuses carried out in research on human beings.

For a long while the so-called principlist doctrine had a decisive influence on its evolution. This doctrine was founded basically on four central principles: two of a deontological nature (justice and no malfeasance) and two of a teleological nature (autonomy and charity).

Little by little, its limitations became apparent, both with regard to its ability to respond to the new challenges of science, and to reflect the economic and social problems that were already clearly showing their impact on life and health in large population centres. In particular, it became apparent there was a growing gap between the extent of the reach of the principlism and a reality that was pushing for answers to the tangible social problems burdening human life.

In voicing these contradictions, the famous Italian bioethicist, Giovanni Berlinger, observed that bioethics emerged in countries of the North to face problems that mainly affect countries in the South. Their elites did not understand a reality beyond the designated limits of the discipline. It became clear that to continue the practice of rigid bioethics with a narrow perspective, limited to medical issues, and with no regard for the context that created those issues, would only widen the gap separating countries in the North from those in the South.

Confronted with this situation, several bioethicists, mostly from the South, conceived the need for a change that without abandoning the content of 'classic' bioethics, would focus on linking it to the problems affecting the life and development of human beings, especially extreme poverty and increasing damage to the environment. That involved incorporating other disciplines into the debate, essentially politics, the economy and ecology.

While these concerns were being tackled, there arose a debate among those fighting to cling to the 'purity' of the discipline and those fighting to open up the field and incorporate contributions that might allow a greater focus on reality. Some clung to the original concepts, while a considerable number of bioethicists gave their wholehearted and vociferous support to the winds of change, bringing political support. I particularly recall the Cuban, Sotolongo,¹ who considered that the defence of apolitical bioethics was a political stand that objectively favoured the conciliation of interests within the bounds of the status quo currently in force. Confirmation of that movement's strength came in 2011, when the Bioethics Congress in Brasilia debated under the meaningful slogan: 'Bioethics, Power and Injustice', which clearly showed where the winds were blowing in Latin America and the Caribbean.²

To a great extent, the fruit of these efforts was the 2005 Universal Declaration on Bioethics and Human Rights, in the final draft of which was a paper by the bioethicists of Latin America and the Caribbean. Running through that text we can observe that far from the principlist doctrine there exists a knowledgeable network with politics that converts it into a powerful instrument of change. A glance at some of the notes is sufficient: the connection of human beings with their environment and with those who live there; the concern about social determinants with regard to health, about interculturality, and about fair participation in the findings of scientific research. Far from being just another proclamation, it became a guide for seeking effective solutions to the problems affecting human beings in the fields of life and health. A central aspect of the Declaration is the way bioethics and human rights are linked together.



1 Pedro Luis Sotolongo is a researcher at the Institute of Philosophy, Academy of Sciences, Cuba. Among his publications the following stand out: 2006, *La Revolución Contemporánea del Saber y la Complejidad Social*, Texas, CLACSO; 2007, (ed.) *Reframing Complexity: Perspectives from the North and South*, Mansfield, ISCE Publishing.

2 IX Congresso Brasileiro de Bioética e I Congresso Brasileiro de Bioética Clínica, 2011.

Human Rights constitute an aspiration widely longed for over the course of history. Despite some lukewarm indications such as the Virginia Declaration of 1776 and the French Declaration of the Rights of Men and the Citizen of 1789 along with that of 1948, they had a tangible influence at international level. It was the summary of a consensus representing a moral conception common to governments and populations. Bobbio considers it to be the greatest historical truth that has ever enjoyed universal agreement on a particular set of values. What should be highlighted is that based on the 1948 Declaration, there arose a movement that gave new impetus and kept human rights from being forgotten.

As Rabossi³ shows, from the 1948 Declaration there developed a phenomenon that was legal, political, ideological and moral. It was extremely dynamic, of global reach and had revolutionary consequences. This process was in a constant state of preparation which enabled it to incorporate new rights and, essentially, to demand that those already incorporated should validly be applied to the actions of the new institutions (international courts of human rights, International Criminal Court, etc.) or of the creation of non-governmental organizations which are ready to deal with any violation of these rights on a global scale. With regard to human rights, these should be moved to bioethics if we sincerely want them updated to meet current needs. For its part, the 2005 Bioethics Declaration, which we consider to be a central instrument, should be converted into a guide for action. Each of the principles set out justifies joint action whose realization is the responsibility of all those for whom it is intended. They are the ones who should take action so that the principles promised can become tangible reality. Through the many achievements of science and technology that never cease to amaze us, we witness scenes unworthy of the human species. The chaos

The 2005 Declaration, in one of the most lauded sections, refers to social responsibility in health, beginning by pointing out that the promotion of health and social development for populations is an essential mission for governments, shared by the whole of society

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of extreme poverty, social exclusion and fratricidal struggles constitute a challenge for those who say they demand the concept of human dignity.

The 2005 Declaration, in one of the most lauded sections, refers to social responsibility in health, beginning by pointing out that the promotion of health and social development for populations is an essential mission for governments, shared by the whole of society. But idleness, lack of interest, corruption, the ineptitude of governments, together with the inhabitants' lack of concern, push the problems of life or the social development of human beings into the background to the extent that they are simply forgotten. This is where people and organizations should be taking action, to raise people's awareness and call for the proclaimed rights to become effective. On this subject, bioethics and human rights must combine forces in order to call for the effective application of social and economic rights, which should be the central pillar for bioethics in the twenty-first century.



From the outset, UNESCO has played a central role in the development of bioethics, especially in Latin America and the Caribbean. Here, it should be recalled that the two declarations on the human genome and on bioethics and human rights, far from constituting theoretical contributions, have influenced the implementation of public policies and have served as a basis for legal decisions. The 2005 Declaration constitutes a guide for action with which to face the coming years. The shared use of the benefits resulting from scientific research, the protection of the environment, the biosphere and biodiversity, the evaluation and management of risks linked with medicine, life sciences and corresponding technologies, international cooperation, respect for cultural diversity and pluralism, human vulnerability – all are subjects that require better theoretical preparation, as well as respective action to carry them out. The Declaration as a guide can be improved and should be revised in the future to demonstrate its flexibility in the face of new challenges and to extend its content even further.



Results and prospects of promoting bioethics

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Twenty years: a life-time of functioning, at the end of which, traditionally, human organizations feel the need to stop and evaluate their action, take stock of their results and take a look at the different routes opening up. Twenty years after it was created, the Bioethics Programme is no exception to this kind of questioning, demonstrating its objectivity in the choices to be made for its possible future.

This Programme can be summarized by its three main lines of action: firstly, the drafting of normative instruments; next, information and awareness-raising among the different actors in bioethics (researchers, lawyers, political decision-makers, the general public, etc.) who understand the conception and the dissemination of basic information and teaching material, the creation of a database; and thirdly, capacity-building, including individual training and help for institutions in Member States in the setting up and/or functioning of bioethics committees.



The Bioethics Programme can boast of undertakings that have had a major impact on the promotion of bioethics through various activities: the creation of a workplace which has enabled inclusive, democratic debates, leading to the adoption of the three great Declarations with which we are familiar: 1997, 2003 and 2005; and the publication of reports on specific issues, notably those relating to the principles of the Universal Declaration on Bioethics and Human Rights (UDBHR), the production of much-needed training material on bioethics, especially in French-speaking countries, and help with the new national bioethics committees all over the world.

This driving force, while representing considerable progress, highlighted certain limits or constraints that could hinder its smooth operation and raises questions on the overall impact. The overlapping of subjects among the various United Nations agencies

appears to be often more of a hindrance than one of synergy and raises the issue of maximizing coordination.

Furthermore, there is real evidence to show that there is a long way between the adoption of Universal Declarations and practices being harmonized in all countries. The same can be said when one considers the creation of national bioethics committees and their impact on national legislation or the awareness of political decision-makers and the general public. One of the problems lies in the way in which these committees are created, sometimes purely within the confines of academia, resulting from the commitment of individuals, and often without real involvement on the part of political decision-makers. Moreover, the lack of effectiveness sometimes comes from a lack of proper involvement on the part of National Commissions for UNESCO, which in some countries have neither the necessary expertise nor the perception that bioethics could be part of their range of activities, as it represents a cross-cutting discipline, subject to the action of several ministries: those in charge of health, of science and technology, of higher education, research or the environment.

Furthermore, the search for consensus comes up against several confrontations: from that between the principles of bioethics and scientific or differing economic interests, to that resulting from different philosophical approaches, and that of very differing cultural sensitivities. This culminates in a difficulty in reaching a consensus on topical issues such as cloning or traditional medicine, sometimes going as far as differences of opinion on formulation or terminology. Of course, some of these constraints are not specific to the Bioethics Programme, but they represent challenges that must be overcome in order for the Programme to become more efficient.

Another consideration is the training of bioethics teachers. In fact this Programme seems to us to be too restricted for it to have any real impact. These restrictions can be noticed in the number of training sessions, their geographical distribution and the language in which they are taught. French-speaking countries in particular are penalized by a lack of teaching material in French and by the limited number of existing training centres. This is all the more important as the bioethics training system is practically non-existent in the academic areas which are not English-speaking and thought should be given to this with a view to introducing bioethics into curricula and establishing specialized channels.



What work prospects do we have in store? Our views lie along two lines of thinking that seem to us to take priority because of what is at stake for the future. The first line is that represented by legal and social ethical issues raised by research in genomics. The research team in the ethics of 'omic' sciences embarked on some interesting work on the impact that the genomic sciences could have on different aspects – ethical, legal and social. We have picked up on some of these aspects which should be given particular attention by the Bioethics Programme:

- ❖ firstly, the scientific challenges and ethical issues raised by the selection of participants and representation in genomic research of minorities and populations of all ages throughout the world;
- ❖ secondly, the controversies linked to the use of the notion of 'race' and ethnicity in biomedical research versus the under-representation of populations in developing countries and/or of ethnic minorities with, as a possible consequence, a limitation of the feasibility of generalizing the findings;
- ❖ finally, the possible exclusion, owing to lack of interest on the part of financial backers, of illnesses specific to countries with limited resources for genomic research.

The second line of thinking concerns the challenges posed by the prospect of the integration of genomics into public health research and health policies. In effect, the advances of genomics in understanding the connection between genes and pathologies involve future conceptual changes both in public and therapeutic health, particularly with the emerging concept of personalized health interventions. Health systems as well as health policies and practices will need to meet the challenges posed by the future integration of genomics and they will need to find a balance between the protection of individual interests and the advantages of implementing measures that have arisen from the progress of genomics for entire populations.¹

What challenges? There are many challenges for such a Programme; some have been talked about with brio, for instance the unprecedented unanimous adoption of the UDBHR. However, other challenges seem to warrant particular attention. At the global level, we have the confrontation in real life of bioethical principles of solidarity,

1 M. Stanton-Jean and B. Godard, 2008, Santé, éthique et bien commun : que voulons-nous dire?, in B. M. Koppers and Y. Joly (eds), *Le bien commun et la santé*, Montreal, Thémis.

international cooperation and social responsibility. Reality forces us to admit that various financial interests, protectionism and diverse political leverage and the financial power of countries, the undue influence of large international corporations – all are obstacles to the effective translation of these principles into international action and decisions. The main challenge for UNESCO and other Agencies of the UN can be put like this: what action should be implemented by these different institutions in order to make these principles reality?

For countries in the South, the major challenge lies in the necessary transfer between expertise and individual engagement in the field of bioethics and national awareness or political involvement with a certain number of issues to be addressed, for example: how should this transfer be carried out? What role can the National Commissions for UNESCO play? What role should be played by the UNESCO Chairs? What is the role of the Intergovernmental Bioethics Committee? Are the national bioethics committees really national? What should their link be with the policy-making institutions?

In its conclusions, the JACOB International Experts Conference, co-organized by UNESCO, the World Health Organization, the European Commission and other international agencies, reflects some of these concerns and gives recommendations that aim to confront these challenges. Countries have thus been encouraged: to set up independent, multidisciplinary, multisectoral bioethics committees at national level and to provide them with the means for effective engagement in the ethical debates raised by inequality of access to health care, the advances of science and the new biotechnologies. They were also encouraged to establish competent governmental policies as well as the related rules and regulations. Furthermore, UNESCO was invited, along with other international agencies and international communities to continue their cooperation and increase their promotion of regional bioethics networks in order to facilitate the exchange of knowledge and best practices with regard to bioethics issues of universal interest.²

Bioethics for all. The main challenges for UNESCO's Bioethics Programme in future years may be those of pragmatism in its implementation, of the opening out the United Nations system to other bodies, in terms of the recognition of bioethics, its inclusion in agreements and conventions, and in the management of political issues linked to bioethics. The challenge: bioethics for all.



2 European Commission-UNESCO Conference: Joint Action for Capacity-building in Bioethics (JACOB), Conference Report, Mexico City, 26-28 November 2009.

UNESCO facing the global demand for ethics

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The new technical possibilities afforded by the biotechnological and biomedical techno-sciences have transformed human influence out of all proportion. Humanity, under the propulsion of a Prometheus unchained, now finds itself involved in actions whose consequences cannot yet be fully controlled. We have to realize that genetic engineering, medicine and the chemical-physical sciences are posing more problems for humanity than biologists, doctors, physicists and chemists can solve. And the growing concerns are accentuated by multiform ethical demands, ranging from medical ethics through research ethics to eco-ethics. In order to meet these demands, we now have bioethics, 'a privileged field for interaction between the symbolic and the techno-scientific'.¹

Bioethics enjoys the privilege of shedding light on or resolving in a multilateral, multidisciplinary and transdisciplinary manner, any problem of ethical dimensions that is posed by the development of biomedical and bio-technological techno-sciences. Furthermore, it has the particularity of seeking to resolve issues by taking into account the dual nature of those problems (multiculturalism and technological-scientific research) and by the clarification of principles and procedures of a rational structure of values claiming to be universal by the dialectic of 'principlism' and rational casuistry.

From this point of view, the exemplar of bioethics to respond to the demand for ethics may be confirmed. This is also the case when describing the position bioethics holds at UNESCO. Indeed, bioethics at UNESCO strives to reconcile its speculative principle² with the essence of UNESCO's Constitution: ethics and the sharing

1 G. Hottois, 1990, *Le paradigme bioéthique*, Brussels, De Boeck University, p.188.

2 'the knowledge of how to use knowledge for the social good...', Extract from the article by V.R. Potter, 1970 and 1971, *Bioethics, the Science of Survival*, translated by G. Hottois, in *Qu'est-ce que la bioéthique?*, Paris, Vrin, p. 11.

of knowledge. This substratum is noticeable in the efforts UNESCO has deployed on the institutionalization-internationalization of bioethics over the past twenty years.



At the outset, there was reflection on the human genome and the actual human being derived therefrom was and still is the origin of bioethics. Before the creation of the International Bioethics Committee (IBC) in 1993, which contributed to the institutionalization and internationalization of bioethics, UNESCO had, in 1989, already set up an international scientific coordination programme on the human genome, known as the Human Genome Project. That committee's task was to promote access to the new knowledge accumulated during its realization. In 1997, at its twenty-ninth session, UNESCO produced, with a notable contribution by the IBC, the first normative instrument on bioethics, The Universal Declaration on the Human Genome and Human Rights.³

Even more expressive and significant for bioethicists is the Universal Declaration on Bioethics and Human Rights (UDBHR). This Declaration has the merit of taking into account most of the so-called bioethics issues, particularly those inherent in biomedicine, multiculturalism and the environment. The efforts towards the institutionalization and internationalization of bioethics continued with the creation in 1998 of the Intergovernmental Bioethics Committee (IGBC) and the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST). Using the combined expertise of these three bodies, UNESCO produced the first great Declaration of universal scope with a manifest proximity to bioethics. The text of the Declaration, translated into over thirty languages, has served as a basis for the bioethics training programmes initiated by UNESCO. Two manuals were produced.⁴

Training and the production of bioethics manuals, in cooperation with the Advisory Expert Committee for the Teaching of Ethics and the UNESCO Chairs in Bioethics, are the most significant recent actions in the process of the institutionalization and internationalization of bioethics across the world.

3 We were present at that UNESCO session in the capacity of experts having drafted, at the request of the Côte d'Ivoire National Commission for UNESCO, the Côte d'Ivoire Declaration on the human genome.

4 2008, The UNESCO *Bioethics Core Curriculum*, Section 1: Syllabus Ethics Education Programme, Paris, UNESCO and 2011, UNESCO *Casebook on Human Dignity and Human Rights*, Bioethics Core Curriculum. Casebook series, No.1, Paris, UNESCO.

Institutionalization and internationalization of bioethics: the challenges and what is at stake. While UNESCO has been able to ensure the institutionalization and internationalization of bioethics over the past twenty years, it must be acknowledged there is still a long way to go. The nature of bioethics, the position of UNESCO and the complexity of the issues facing contemporary society make this task an arduous one. There are three major challenges to face and they have different outcomes.

Firstly, to guarantee the permanence of a practice of bioethics consonant with UNESCO's mission, contemporary expectations and finally, the axiological and epistemological substratum of bioethics. In other words, how to ensure the success of UNESCO's ethical mission while backing a flawless bioethics which is balanced and capable of providing an adequate response to the legitimate concerns of contemporary society. Considering bioethics in both the narrow and the wider sense of the term, UNESCO has the merit of practising a bioethics that holds its own against the surgical slashes of 'biomedicine' and the skilful defence of 'bio-rights' and 'bio-politics'. The challenge is dual: to keep among the agencies of the UN the prominence of UNESCO via its position as leader on bioethics and the ethics of science and technology, as well as guaranteeing the best visibility for bioethics.

Secondly, to promote the dissemination of bioethics teaching. Putting bioethics on curricula as a subject that can be taught is the challenge born of the controversy surrounding bioethics as a discipline or as a simple area of reflection. In striving to overcome this controversy, UNESCO combines, not without difficulty, these two conceptions of bioethics fortified by the national ethics or bioethics committees and the UNESCO Chairs in Bioethics. The real challenge to be faced here is that of globalized bioethics teaching, from basic education to higher education. One of the risks of that globalization through 'ethicological' knowledge is the sustainable cognitive appropriation of the principles and values that bioethics promotes through the normative instruments adopted by UNESCO and bioethics manuals. The problematic of the manuals is another challenge to be faced.

To keep among the agencies of the UN the specificity of UNESCO and its position as leader on bioethics and the ethics of science and technology

Thirdly, to produce bioethics manuals that will withstand the globalization of ethics. The manuals produced by UNESCO fall within the framework of the follow-up to the Universal Declaration on Bioethics and Human Rights. The *Casebook Series*,⁵ which is intended to complete or exemplify the *UNESCO Bioethics Core Curriculum*,⁶ is snagged with biomedical concerns. With regard to the *Bioethics Core Curriculum*, for a sharper reflection that takes into account the complexity of the global demand for ethics and the needs for specialized training in bioethics, that basic course should be completed by speciality courses. For basic education, UNESCO should produce a manual whose content is more lightweight.

Looking to the future. Resisting the temptation to reopen the debate on the concept of bioethics upheld by Potter, one cannot but help amplify the idea of a bridge as both a construction and a direction towards the future.⁷ It is a matter of a built, not given, future. Originally oriented towards the future, bioethics is also developing as a prospective approach to issues. When knowledge is to such an extent linked inextricably to the future, opening it up and promoting it means demonstrating one's interest in the future and engaging in long-term reflection and action. In placing bioethics as a sectoral priority, UNESCO has involved itself in the survival of humanity and in 'the permanence of an authentically human life on Earth'.⁸ To keep this commitment, UNESCO could make use of all the Chairs in Bioethics. This is where it should perhaps be underlined that the evaluation of these Chairs should not just be in their mere existence.

Considering the positive aspects of bioethics, those of the complexity of endless questioning, concrete universalism and transdisciplinarity, UNESCO is paving the way for better management of the concerns of the 'sciencephobes' and the 'technophiles' of the twenty-first century.



5 UNESCO, 2011, op.cit.

6 Idem

7 V. R. Potter, 1971, *Bioethics: Bridge to the Future*, Upper Saddle River, Prentice Hall.

8 H. Jonas, 1990, *Le principe responsabilité*, trans. J. Greisch, Paris, Cerf, p. 30.

Bioethics in Belarus: results, problems and prospects

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Since the First International Conference *Biomedical Ethics – Problems and Prospects*, held in Minsk in 2000, bioethical problems have been the focus of the Belarusian scientific and humanitarian community. For Belarus, given the critical state of its nature-society balance, the status of bioethical parameters is of paramount importance. Biomedical research data demonstrate that public health and genetic funding are under direct threat, especially given radiation and chemical contamination levels of the territory as a result of the Chernobyl catastrophe. That is why modern bioethical models and the development of biomedical research programmes, though adapted to the public health system of the republic and its scientific, socio-cultural, legal and philosophical traditions, require further theoretical and practical development.

Currently, Belarus has objective and subjective conditions for developing the institutional foundations of bioethics. Since 2000, ethical expertise of pre-clinical and clinical research, and of medical technology, has been led by a network of local ethics committees at public health institutions and medical universities, regional ethics committees and, at national level, committees and centres for bioethics in research. The National Bioethics Committee (NBC), created in 2006 in Belarus under the aegis of the UNESCO Moscow Office and the National Commission of Belarus for UNESCO has the following functions: monitoring human rights in light of biomedical ethics criteria; conducting fundamental bioethical research related to human and moral values of biomedical achievements; providing independent appraisal, consulting and decision-making in biomedical, genetic and other research areas with human-animal participation; evaluating ethical, legal, and social issues related to biomedical research.

Educational activity is one of the priorities in developing bioethics in the Republic of Belarus. We have developed undergraduate programmes (Fundamentals of Biomedical Ethics) and medical postgraduate programmes (Current Issues of Biomedical Ethics). In 2001, the International Sakharov Environmental University (ISEU) introduced the Fundamentals of Biomedical Ethics study course. The courses and programmes have been well supported with textbooks, manuals and research materials.

In 2009, the ISEU signed a memorandum on piloting a bioethics course developed in 2008 by the UNESCO Division of Ethics of Science and Technology on the basis of the 2005 Universal Declaration on Bioethics and Human Rights (UDBHR). This constituted a real breakthrough in the system of bioethical education. In 2010, the UNESCO foundation programme served as the basis for developing and introducing innovative programmes on biomedical ethics at the Environmental Medicine Department of the ISEU.

However, achievement of the wider objective depends on the definition and solutions to the range of problems in specialist bioethical education. The questions: 'What should we teach?', 'Whom should we teach?' and 'Who should be the teacher?' are key problems, not only for Belarus, but for the whole international community, thus requiring UNESCO's assistance in organizing their discussion.

The answer to the first question is within the scope of bioethics principles and norms defined by UNESCO in its Universal Declaration on Bioethics and Human Rights (UDBH). The answer to the second question reveals such a diversity of groups requiring bioethical education (medical specialists, government officials, bioethics specialists, trial participants, etc. – to name but a few) that it could justifiably be claimed the bioethical education is needed for the general population. The inadequate level of education in ethics is a problem not only in Belarus and other post-Soviet countries; it is prevalent in many other countries as well. What was previously considered a satisfactory level of medico-ethical education has a traditional patronizing-paternalistic character. We must reconcile the fact that a human right to life and death is the right of a human and not of his/her doctor, researcher, or legislator. This requires the adoption of a new humanitarian ethical attitude through bioethical education based on, *inter alia*, the UDBHR. The third question is still open for discussion. Who should teach bioethics – specialists in medicine and biology or specialists in ethics? There are arguments *pro* and *contra* for both sides – and the truth is somewhere in the middle. Specialists in ethics should perhaps first educate teachers of medical sciences in ethics and bioethics, and then through their

collaboration, both groups should provide bioethical education for the rest of the population.

Another exceptionally important trend in bioethics development in Belarus has been the creation of a conceptual theoretical model of bioethics and the subsequent development of the mechanisms of its application to specific areas of biomedicine. Of late, Belarusian specialists have been focusing on researching practical aspects of bioethics – in particular, in the sphere of biomedical and genetic research. In 2005-2007, in collaboration with the Institute of Philosophy of the Russian Academy of Sciences, we worked on socio-philosophical and ethical problems of genome research and clinical medicine, leading, in 2008, to a collective monograph *Bioethics and Humanitarian Appraisal: Problems of Genomics, Psychology, and Virtualistics*. In 2010-2012, in collaboration with the State University of Medicine and Pharmacology of Moldova, we worked on a bioethical foundation for medico-biological and genetic research, leading to a four-volume publication: *Strategy of Safe Development of Modern Civilisation in the Context of Bioethics, Philosophy and Medicine*.

Nevertheless, numerous theoretical and practical ethical problems in the sphere of biomedicine have not been adequately developed, remaining ‘open’ and, in our opinion, requiring public discussion which might be initiated by UNESCO:

Numerous theoretical and practical ethical problems in the sphere of biomedicine have not been adequately developed, remaining ‘open’, requiring public discussion which might be initiated by UNESCO

- ▼ Research into specifics and differences in ethical, ethico-legal and ethico-religious approaches to understanding the essence and peculiarities of traditional moral values manifest in biomedicine;
- ▼ Ethico-philosophical analysis of categories previously omitted from the scope of traditional ethics, i.e. life, death, their criteria, including the beginning and end of human life;
- ▼ Solutions concerning the status of the human right to life and death, status of the embryo, moral problems of artificial insemination, cloning, human genetics, transplantology, reanimatology, euthanasia etc;

- ▼ Understanding certain traditional norms of medical deontology in light of modern requirements of humane ethics;
- ▼ Expansion of the scope of bioethics problems by including eco-ethical issues to protect the rights of all living beings – in particular in biomedical research, i.e. actual conversion of bioethics into global bioethics;
- ▼ Solutions regarding the status and relativities of bioethics, global bioethics, medical ethics, and their legal parameters.

The above issues call for UNESCO's special attention and necessitate further studies, systemization and the development of biomedical ethics.

In the last three years, ISEU (in collaboration with the National Academy of Sciences of Ukraine) has focused its research on the bioethical aspects of the application of advanced technologies – in particular, nanotechnologies and nanomaterials in medicine, genetics and human ecology. Based on the defined principles, norms and imperatives of nanoethics, we have drafted the *Code of Ethical Rules*, included in the UNESCO Programme's Bioethics course. The Code should provide biosecurity for biomedical and genetic research. It contains practical recommendations and rules for applying and controlling nanotechnologies and nanomaterials by public health institutions, pharmaceutical companies, commercial corporations, doctors and patients.

In our opinion, the following six directions and trends serve as prospects for further research and implementation of ethical aspects when using nanotechnologies in biomedicine and human ecology:

- ▼ Further development of the conceptual model of nanoethics as a methodological foundation in order to evaluate the application of nanotechnologies and nanomaterials in clinical medicine and research involving human subjects, on the basis of the UNESCO's UDBHR;
- ▼ Theoretical analysis of nanoethical problems of ecological risks caused by the development of nanotechnologies and the possibilities for interaction between nanoethics and ecological ethics within the general scope of human ecology;
- ▼ Analysis and development of theoretical foundations and possibilities of applying organisational ethics in nanoethical practice (with organisational ethics in biomedicine making correct ethical decisions for institutions tasked with finding and developing mechanisms of institutional ethical control over the application of nanotechnologies);

- ▼ Research into socio-ethical issues relating to the risks of abusing achievements of nanotechnologies through the commercialisation of biomedical and genetic research, on the risks of cultural and demographic shifts from traditional forms of family and marital relations, and on the appearance of negative neo-eugenics;
- ▼ Study of moral perspectives of the influence of nanotechnologies on solving fundamental problems of biology and clinical medicine – in particular, diagnostics, detecting genetic predisposition to certain medical conditions, prevention and treatment of human medical conditions and anomalies of human development;
- ▼ Development of a system of operational ethical standards and procedures for regulating the application of nanotechnologies and nanomaterials in the sphere of biomedicine and genetics – with the aim of controlling unjustified interference in the human genome and preserving the existence of the human biological species.

Currently, UNESCO supports research into the bioethical aspects of applying advanced technologies in medicine and genetics, with the aim of protecting human ecology. This is one of the strategic directions of world science. The UNESCO Moscow Office has always been instrumental in this process. We feel that it would be extremely pertinent to hold a scientific/practical seminar or conference on the ethical aspects of developing and implementing innovative technologies, in particular for the UNESCO Moscow Office cluster countries.



Promoting the future of Bioethics

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Since its establishment in 1945, UNESCO has committed itself to help establish peace between nations on the basis of humanity's moral and intellectual solidarity. As a goal of UNESCO, such solidarity can be enabled among nations by, for example: mobilizing educational resources so that every child, regardless of its gender, has access to quality education as a fundamental human right and as a prerequisite for human development; building intercultural understanding through the protection of heritage and support for cultural diversity; pursuing scientific cooperation such as early warning systems for tsunamis or trans-boundary water management agreements; or by protecting freedom of expression – an essential condition for democracy, development and human dignity.¹ It has been understood since UNESCO's foundation that science in particular could contribute to peace, security and human welfare but only if its applications are related to a general scale of values. This explains why 'since its foundation, UNESCO has been concerned with moral issues in relation to science'.²

Since the 1970s, biosciences and biotechnology have developed rapidly, raising various new ethical issues. This accelerated development of bioscience and biotechnology explains why bioethics still matters, and will continue to matter as long as bioscience and biotechnology develop. The more powerful our scientific tools become, the more rapid must be our ethical progress if we wish to see ethically responsible usage of science and technology.

The course of UNESCO's action should differ from one region to another

1 UNESCO. <http://en.unesco.org/about-us/introducing-unesco>

2 H. ten Have, 2006, UNESCO and ethics of science and technology, in *Ethics of Science and Technology, Explorations of the frontiers of science and ethics*, Paris, UNESCO, p.5.

This is what UNESCO has been doing at the global level since the 1970s. One of its main achievements in promoting bioethics is the establishment of the International Bioethics Committee (IBC) in 1993. This committee unites 36 experts from all disciplines and all regions of the world, serving in their personal capacities, providing recommendations concerning difficult bioethical issues. At the request of the Member States, it assisted in the drafting of normative standards to provide a framework of bioethical principles for all countries. In 1997, the General Conference of UNESCO adopted the Universal Declaration on the Human Genome and Human Rights, followed in 2003 by the adoption of the International Declaration on Human Genetic Data, thus reinforcing UNESCO's role in setting global standards. Such global standard-setting culminated in UNESCO Member States' unanimous adoption of the Universal Declaration on Bioethics and Human Rights (UDBHR) in October 2005. It was understood by UNESCO that the creation of normative standards would not be sufficient. In order to apply the standards and make them work in practice, capacity-building activities have been initiated, for example the promotion of ethics teaching, the establishment of ethics committees, and the exchange of experiences in ethics³.



Though 'the global nature of science and technology implies the need for a global approach to bioethics',⁴ the focus of UNESCO's activities should vary from one region to another. Identifying and trying to reach basic principles and shared values on a global scale – as was the aim of the above declarations – is not enough. The course of UNESCO's action should differ from one region to another. Some regions such as the Arab world need the help of UNESCO as a reputable and neutral body to advise and encourage their governments on the need for adequate ethics infrastructures, educational programmes and legal frameworks, to ensure their acceptance and to adopt the common principles that unite them with other regions. An example of the vulnerability of the ethics infrastructure in the Arab region is the absence, or inactivity, of national bioethics committees. According to results obtained from the Global Ethics Observatory (GEObs 2),⁵ only eight Arab States – out of twenty-two – have established some kind of a national bio-medical ethics committee: Egypt,

3 2006, *The Ethics and Politics of Nanotechnology*, Paris, UNESCO, pp. 3-4.

4 H. ten Have, The activities of UNESCO in the area of ethics, in *Kennedy Institute of Ethics Journal* 16, no.4, p. 338.

5 See GEObs2: <http://www.unesco.org/new/en/social-and-human-sciences/themes/global-ethics-observatory/access-geobs/>

Jordan, Lebanon, Libya, Saudi Arabia, Sudan, Syrian Arab Republic and Tunisia⁶. Morocco and Oman have committees that are merely connected to universities (GEObs 2). Whether the committees in these eight Arab states are active or not is a controversial point.

An example of the vulnerability of ethics regulations in the Arab world is the research done by Arab experts in bioethics, initiated and published by the UNESCO Cairo office in 2011, on exploring the regulations for important bioethical issues in the Arab world. The research has shown that most of the Arab states lack regulations for such bioethical issues. UNESCO, as a neutral body, should submit the results of such research to the governments of the Arab states, encouraging and advising them on the need for legislation on such important bioethical issues.

Ethics education programmes in the Arab world also need to be reinforced. Since raising public awareness of ethics is an important step in reinforcing the ethics infrastructure of any community, and school and university students constitute the widest sector in any community, equipping them with ethics education will help achieve this, and prepare current and future generations to take an interest in ethics. Bioethics education is absent in nearly all schools' curricula. In universities, according to the GEObs, the Arab world currently offers 28 ethics education programmes in its different states; 27 of which are in the area of bio/medical ethics: Algeria (2), Morocco (2), Tunisia (9), Egypt (1), Jordan (1), Lebanon (3), Syria (3), Qatar (1) and Saudi Arabia (5) (UNESCO: GEObs3). Some Arab States, such as Morocco and Syria, have received training from international organizations such as UNESCO and World Health Organization on bioethics curricula, consisting of technical support and an exchange of expertise from UNESCO's Ethics Education programme. Such programmes are not enough to achieve the goal of raising awareness in the Arab community and prepare the current and future generations to take an interest in ethics.

By the unanimous adoption of the UDBHR, the commitment of the international community was agreed by governments that do not necessarily represent, or always work for, their peoples. At least, this is what the most recent revolutions in some Arab states have revealed. UNESCO needs to find a way to focus its actions on reaching the target nations themselves, the vulnerable groups rather than getting acclamation from governments. Promoting regulations on bioethics such as that done by the three well-known Declarations

6 According to Abdulla Hattab, there is also a national bioethics committee in Yemen. See A. Hattab and J.R. Acosta, 2004, Bioethics in the Arab world. The experience of Aden School of Medicine, in *Revista Latinoamericana de Bioética* Vol. 6(88), p. 7. <http://www.umng.edu.co/documents/63968/78033/rbioetica6.pdf>

referred to above, puts the responsibility for their implementation into the hands of governments. There is evidence that this is not always done.

Another important area for UNESCO action, via the Bioethics Programme, is environmental ethics, as environmental issues should not be tackled separately from bioethical issues. Issues of environmental ethics were already included in the UDBHR and the Bioethics Core Curriculum published in 2008. However, important publications on environmental ethics were issued by UNESCO through the work of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST), such as *Environmental Ethics and International Policy* (2006) and the *Ethical Implications of Global Climate Change* (2010), giving the correct impression that environmental concerns are different, or should be separate, from bioethical concerns. In addition, the UNESCO Bioethics Programme should take a greater interest in environmental ethics.

For some time, UNESCO has adopted what is known as 'best practice'. UNESCO should now apply this to its own activities. Following the success of the Bioethics Core Curriculum, which has been adopted by twenty universities throughout the world, a similar core curriculum on environmental ethics should now be designed and implemented. This should be a collaborative effort between the Bioethics Programme and COMEST, incorporating the ethical principles that can help manage the ethical challenges resulting from the scientific and technological developments, in order to preserve a stable planet that comprises healthy living and non-living organisms.

A Declaration on environmental ethics, similar to the UDBHR should be adopted, where all Member States agree to protect the whole environment as the heritage of humanity. Though this may be politically difficult, UNESCO is in the best position to achieve this. Since UNESCO's goal is achieving peace through intellectual solidarity, and intellectual solidarity is, in a sense, the effort to remove all manner of walls⁷, being Member States of UNESCO obliges all nations to cooperate to protect the environment, which is considered to be human heritage.



7 L. Reyhler, 2010, *Intellectual Solidarity, Peace and Psychological Walls*. 'A World without Walls 2010' An International Conference on Peace building, Reconciliation and Globalization in an Interdependent World, Berlin. <http://www.diplomaticthinking.com/diplomaticthinking/wp-content/uploads/2011/09/psychologicalwalls.pdf>

The challenge of ageing

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It is estimated that in the year 2050, one fifth of the population will be older than 65.¹ The average number of years a population lives has varied throughout history. In Ancient Greece as in Ancient Rome, longevity was considered to be 28 years. In the early nineteenth century it was 30 to 40 years and this figure rose to become 50 to 65 at the beginning of the twentieth century. These changes are due more to improvements in drinking-water systems, health care and education, than to the advances of medicine, which also explains the difference in life expectation between poor and rich countries. The increase in the number of old people brings with it an enormous challenge for society as a whole;² some elderly people have physical difficulties or some kind of cognitive impairment, others require another type of support, entailing social and financial burdens and necessitating political, medical and ethical responses. Another issue that needs to be settled is whether the care of the elderly is the responsibility of family or the State.

The ethical dilemmas relating to ageing and the end of life have much to do with the possibility that autonomy is, to a great extent, diminished.³ Likewise, the increase in life expectancy and the existence of a large number of old people, pose serious difficulties with regard to the assignation of resources and require solutions. It is important to bear in mind that old people contribute financially to systems of insurance and health and nowadays face ridiculously early retirement which also erodes their material autonomy. In the past, 65 years of age meant retirement and there was a clear line

1 2011, *Global Population Ageing: Promise or Peril*, Geneva, World Economic Forum.

2 2012, *Ageing in the Twenty-First Century: A Celebration and a Challenge*. United Nations Population Fund and Help Age International.

3 G. J. Agich, 2001, Implications of aging paradigms, in *Bioethics Vol.10 – Aging: Culture, Health, and Social Change*, International Library of Ethics, Law, and the New Medicine, Dordrecht, Boston: Kluwer.

between the different stages of work and leisure. But nowadays, many people find themselves obliged to take on new responsibilities and activities, which means we need to alter the meaning of being old and/or retired.

Some writers consider that bioethical thinking on ageing also involves something more than the aspects mentioned above. In their text, Holstein, Parks and Waymack⁴ describe many of the central points with regard to the problem of ageing. The authors state that, given the situation of dependency and lack of autonomy that can happen to people of advanced years, the application of the principle of autonomy gives rise to further problems, especially for people living in homes for the elderly or other institutions responsible for their care.

For this reason, they put forward the concept of relational autonomy,⁵ a feminist rethinking of the notion of autonomy,⁶ which involves taking into account the effect of external factors on the individual. In effect, the traditional principle of autonomy does not take into account the nature of dependency and vulnerability of the person. According to these authors, relational autonomy underlines the conditions of possibility of autonomy; the central concerns of the relational perspective can only be understood in relation to its own context of interaction.

The aim is to establish the need for public policies that will provide support for the well-being of the elderly, without gender discrimination and including those who have financial means and/or no physical problems. It is interesting to note how the text of Holstein et al. analyses the significance of concepts like productive ageing, civic commitment, and successful ageing, pointing out that these notions correspond to the fraction of the elderly who are in a good financial situation and enjoy good health, and here, it has to be borne in mind that this is an option accessible to only a few. The authors also tackle the need for supporting third parties (usually the family) and in particular women, where caring for others is unpaid work. As Lisa Eckenweiler points out: 'the work of these carers, most of whom are women, represents a critical mass of the combined total of health workers'.⁷

On the other hand, Agich, a philosopher who has devoted himself to these issues, considers autonomy in old age should have

4 M. Holstein, J.A. Parks and M. Waymack, 2011, *Ethics, Aging, and Society. The Critical Turn*, New York, Springer Publishing Company, LLC.

5 C. Mackenzie and N. Stoljar (eds), 2000, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, Oxford, Oxford University Press.

6 J. Downie and J. Llewellyn (eds), 2011, *Being relational*, Vancouver, UCB Press.

7 L. Eckenweiler, 2013, Introduction, *IJFAB*, vol.6, No.12, *Special Issue on Aging and Long-Term Care*.

a far broader meaning. It should contribute to maintaining self-esteem that is altered due to concerns about ageing and drawing nearer to death, as well as some diminished capacities and increasing dependence on others.⁸ Such support becomes unavoidable in Western societies where independence and autonomy are so highly valued. Agich also points out that, traditionally, greater wisdom and experience is attributed to the elderly because they are deemed worthy of respect. In order to value the elderly, he says it has to be understood that they are not necessarily strong and independent and that the story of who we are is told by the elderly, however fragile or incapacitated they may be.

Personal identity poses a complex problem. What is the moral weight of decisions, beliefs and earlier values, from having sworn they would never live in a home for the elderly, to preferring to be dead than dependent? What weight do their expressed wishes carry? What can be the decisions with regard to foreseen difficulties? Should one respect those preferences expressed by someone who is no longer the same person? Every day, families have to resolve ethical issues such as these and in the end what is being sought is help for the elderly so that they feel comfortable, looked after and safe in their current circumstances. This, in turn, is in relation to the resources necessary for their health care and well-being, which poses a problem for society. Costs rise with the increase in the number of old people and raise issues of fairness and allocation of resources, because the way in which funds are used affects and cuts across all generations. Funds allocated for the elderly is money which will not be available for education, medical care or other social services for young people, but we must not forget that it was these people, now old, who generated part of those resources through their tax contributions throughout their working life.

Elderly people should be considered as specific individuals and not as abstractions, and that we must understand the need to respect their individuality, their affective, personal experiences and accept their habits and wishes

8 G.J. Agich, George J, 1996, Ethics and aging, in D. C. Thomasma and Th. Kushner (eds), *Birth to death, science and bioethics*, Cambridge, Cambridge University Press.

We are immersed in a society that tends to discriminate against the elderly or to treat them like children. Society does not appreciate old age or fragility. Agich says that any analysis, description, estimation or report on ethics and ageing should include the prejudices on the subject, and that unfairness is not recognizing that old people must be respected for who they are: adults.

We often have to opt for only one of two alternatives, where both are equally worthy and correct. In the case of a father with a chronic illness, how can his health care be compatible with caring for our own family, parents and children?⁹ In the case of instructions written by a person in anticipation of his/her possible future incapacity, when is the right time to put those instructions into practice? And what if those instructions run counter to the beliefs and prejudices of the person who has to carry out those instructions? Thus, we find ourselves questioning whether or not to respect to the letter the autonomy of a particular adult who may have complex problems where ageing, illness or suffering involve dependency and vulnerability which require support. It becomes difficult for those involved to decide between help to carry out everyday tasks and rejection of the assistance that they need. It is not easy to ask for help or to accept that we cannot manage on our own.

For all these reasons, I propose that elderly people should be considered as specific individuals and not as abstractions, and that we must understand the need to respect their individuality, their affective, personal experiences and accept their habits and wishes.



9 R.M. Kidder, 2003, *How good people make tough choices: Resolving the dilemmas of ethical living*, New York, Harper.

Building our own bioethics, set in context and legality

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Bioethics first came into being in the 1970s in the United Kingdom and the United States, before spreading gradually to Latin America, Europe, Asia, the Middle East and Africa. With it came the key concepts and values, along with the biological, medical and biotechnical issues that characterize bioethics. Thus, today, people from all walks of life who take part in the development and institutionalization of bioethics, find themselves facing the challenge that although bioethics has now become international, it has not been internationalized to the same extent.

In this respect, in a region like Latin America, noted as being one of the most unjust and inequitable in the world with regard to the distribution of income and opportunities, where the effects are still felt of past exploitations of different ethnic groups and the subordination of women, where the economic growth model is proving incapable of raising hundreds of millions of people out of extreme poverty, and where one-third of the population still has no access to basic health care, ethical reflections on life and health are obliged to be open to other areas, especially those concerning the determinants of public health.

Within this context, the Latin-American and Caribbean Bioethics Network (Redbioética) emerged as an extension of UNESCO's¹ Bioethics Programme, which aims to generate, inform

1 www.unesco.org/uy/shs/red-bioetica/es/quienes-somos/red-latinoamericana-y-del-caribe-de-bioetica.html

and promote academic activities, teaching and research, make publications and information on topical bioethics available to experts and non-experts, and to open up debate on matters both old and new, which require reflection and resolution in the region with the region's codes.²

For some time now, efforts have been made in the academic field to encourage the study and teaching of bioethics in Latin America and the Caribbean, but only recently has it been incorporated as a mandatory subject into certain university health courses. Several countries in the region – Argentina, Colombia, Uruguay, Mexico and Chile – have set up important initiatives in education and these initiatives are multiplying at a significant rate.

UNESCO has established four Chairs in Bioethics in the region. One in Argentina, at the University of Buenos Aires; another in Peru at the Women's University of the Sacred Heart; another in Brazil at the University of Brasilia and the fourth in Mexico, at the National Autonomous University of Mexico (UNAM).

Today, over a decade into the twenty-first century, it can be stated that bioethics is present in all countries of Latin America through hospital committees, centres, institutes, forums, conferences, undergraduate and postgraduate courses, master's degrees and national bioethics associations. As a result, with varying scope and in some cases without being exempt from religious connotations, bioethics is a discipline established in all Latin American countries; even jurisprudence in many countries is verifying the bioethical issues that have had recourse to law.³



There has been much debate on whether or not to talk of Latin American bioethics.⁴ There appears to be a tendency towards a positive response from bioethics specialists in the region, for reasons which will be explained further on.

The issues tackled by bioethics are present in all societies. Nevertheless, the context in which the problems are posed is not the same. The aim is 'to reflect on issues which, although of a universal nature, acquire an individual profile' and for this reason, must be analysed alongside the subtleties that occur in our society, which suffers from its own conflicts and limitations, and is infused with its

2 www.redbioetica-edu.com.ar.

3 See M. Casado and F. Luna (eds), 2012, *Cuestiones de Bioética en y desde Latinoamérica*, Civitas, Spain.

4 See S.D. Bergel, 2010, La bioética, in E. Dussel, E. Mendieta and C. Bohórquez (eds), *El pensamiento filosófico latinoamericano, del Caribe y "latino"*, Mexico, Siglo XXI Editores, p.446 onwards.

particular customs, traditions and values.⁵ Perhaps the most symbolic example would be issues concerned with the reproductive health of women. Although one must learn from the experience of other countries, it is not enough to provide solutions without reflecting upon them, since such solutions may have been devised for a different reality and for very different issues and cultures.

Christian Byk maintains that 'Each person should apply his/her own reality to bioethics. If one attempts to use bioethics to disguise a country's problems, it being a new, elegant discipline, then we should take a step back and have no more bioethics. Whereas we need to keep moving ahead if this is an intelligent way of discussing a society's actual, sensitive problems'.⁶

Continuing this line of thinking, in order to adapt and make bioethics more appropriate to Latin American reality, writers are often concerned with focusing on problems from a more social viewpoint, a method that implies passing from bioethics centred on the individual to a holistic bioethics based on social justice and equality, which includes the right to health among economic and social rights.⁷

However, Latin American bioethics must not forget what exactly bioethics is, hence it must be removed from any religious connotation or any political bias. In recent years, especially at the level of jurisprudence, and of local and regional justice, significant progress has been made with regard to issues such as reproductive rights, the ending of life, biomedical research and patients' rights, to name but a few. In any case, to achieve universal respect for human rights, it is absolutely essential that, in the course of the next few years, the region give full

The challenge for bioethics in Latin America is to build a secular bioethics, of equity, of justice, of respect for human rights, acknowledged by the law, especially on issues having a major social impact in highly vulnerable sectors

5 See F. Luna and A. Salles, 1996, Develando la bioética. Sus diferentes problemas y el papel de la filosofía, in *Perspectivas Bioéticas en las Américas*, Año 1 (1), pp.10-22.

6 See C. Byk, 1997, Realidad y sentido de la bioética en el plano mundial, lecture at Universidad Notarial Argentina, published in *Cuadernos de bioética*, n° 1, Ad-hoc, Buenos Aires, p. 61 onwards.

7 See C.M. Cardona Ramirez, 2010, El desarrollo de la bioética en Latinoamérica y el aporte desde el franciscanismo, in *El Agora USB*, Vol.10 (1), pp.243-68. Medelín.

recognition and legal acceptance to bioethics, with regulations that are, naturally, subject to periodic revision.

The challenge for bioethics in Latin America is to build a secular bioethics, of equity, of justice, of respect for human rights, acknowledged by the law, especially on issues having a major social impact in highly vulnerable sectors.

In short, the twenty-first century challenge for bioethics in Latin America is to build a secular bioethics that is equitable, just, respectful of human rights, and acknowledged by the law, especially on issues that have a major social impact in highly vulnerable sectors. By extension, the 2012 project amalgamating Argentina's civil and business code which is sanctioned by half the Senate,⁸ includes some articles of major impact on the field of bioethics in relation to the inviolability of the human person, a person's autonomy over his/her own body, informed consent for certain personal acts, protection of the beginning of life and the regulation of assisted human reproduction, etc. UNESCO's role is crucial for the above project, and it must be aware of the need for education in order to confront these issues in a responsible manner.



8 28 November 2013.

PART FOUR

Towards the Future

Future trends in bioscience and biotechnology and their ethical considerations

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As we enter the twenty-first year of the UNESCO Programme on Bioethics, there are many issues that we need to discuss in looking to the future. Firstly, we have covered so much ground in bioethics, ranging from issues on the broad repercussions of bioscience on the general population in areas such as neuroscience, food and plant biotechnology, on genetic screening, gene therapy and stem cells, and on issues centred around the scientists themselves, such as social responsibility. As we look to the future, although these issues remain largely relevant, they need to be constantly reevaluated because of the new scientific advances which have bearings on bioethical considerations. The International Bioethics Committee (IBC), which was formed twenty years ago, was followed by the Intergovernmental Bioethics Committee (IGBC) five years later. This Committee, with thirty-six member countries, has the task of critically examining the IBC reports, informing the IBC of its opinions and submitting these opinions along with proposals for follow-up of the IBC's work to UNESCO's Director-General for transmission to Member States, the Executive Board and the General Conference of UNESCO.

On the occasion of the twentieth anniversary of the Bioethics Programme, it is therefore pertinent to examine some present and future trends in bioethics. Here, we will examine three key future trends and one current issue, which should be included in the future work of the IBC, and the IGBC of UNESCO.

As Professor John Harris remarked during the Symposium on the occasion of the twentieth anniversary of the UNESCO Bioethics

Programme,¹ bioethics is playing catchup with science, and UNESCO is playing catchup with bioethics. While some may dispute this statement, I also think it is the case. I would also add that developing countries have the unenviable task of playing catchup with all of them. This task is very hard for developing countries, since they are having difficulties both with keeping pace with technical advances, and on catching up with the problems stemming from the broader ethical implications of the new biotechnologies and biosciences. Some future trends with bioethical implications for developing countries are as follows.

Individualized genomics. Issues include increased cost to patients, implications of information for individual decisions, especially when estimating the risks of alternative courses of action, and on privacy. The issue has been highlighted by the decision of a well-known film star to have a radical mastectomy after confirming that she has tested positive for the breast and ovarian cancer gene. This example will be long studied and debated, with such questions as how much an individual is free to decide to take the tests, what are the implications of the result on the individual and on close

The humanitarian imperative for the world to focus more on diseases of the poor in reaping the benefits of new genomics has still not been sufficiently addressed

relatives, what is the accuracy of risk assessment following positive tests, and the financial costs of such tests. In developing countries, however, problems of hype, fraud, misinformation and affordability complicate the issues of individualized genomics even further. These problems concern the ethics of commercialism in activities which are not yet completely free from the risks of uncertainty and failure. Meanwhile, the humanitarian imperative for the world to focus more on diseases of the poor in reaping the benefits of new genomics has still not been sufficiently addressed.

1 Held on 6 September 2013 at UNESCO HQ. Professor John Harris is the Director of The Institute for Science, Ethics and Innovation and of the Wellcome Strategic Programme in The Human Body, its Scope Limits and Future, University of Manchester.

Public health genomics. Stratified medicine is medicine at the public health level, based on genomic and other information (location, social status, behaviour), which stratify the population into groups with collective risks of diseases stemming from genetic, social and environmental backgrounds. It is an important topic for developing countries to consider from a political perspective, especially when this involves limiting the public health resources of developing countries. The greatest advances have been made possible through the integration of genomics and information technology. The likelihood of getting a disease, such liver fluke disease in Northeast Thailand, is an example of the kind of problem that will be informed by stratified medicine. Bioethical issues include moral justification, potential stigmatization and discrimination, misuse of information (akin to the ‘Big Brother’ situation, as in George Orwell’s celebrated novel *Nineteen Eighty-Four*).² It should be noted that Doctor Aissatou Touré³ also mentioned this in her talk. A major problem for developing countries is how much of their limited budget should be allocated to the development of this new area of medicine.

Synthetic biology. It is now possible to make synthetic life for microorganisms from whole genomes (for example, the achievements of Dr Craig Venter’s group).⁴ This ‘life-from-chemicals’ capability could soon be upgraded to include making higher organisms from their genes. Multigene insertion is now possible, e.g. artemisinin production from yeast, genetically modified (GM) mosquitoes which do not carry Dengue hemorrhagic fever or malaria. Synthetic biology could soon evolve enough to allow the modification or creation of life forms with the aim of improving health care or solving environmental problems. However, there are certain risks which must be taken into consideration and their mitigation planned. Bioethical considerations include the assessment of risks and the implications of such undertakings. A parallel development is manufacturing and production using three-dimensional (3D) printing, which can simulate real objects. Such techniques, while not producing living tissues or organs as such, could produce biocompatible parts to replace living tissues or organs.

2 *Nineteen Eighty-Four* is the famous novel by George Orwell, published in 1949.

3 *Intra* Aissatou Touré, pp. 97-100.

4 D.G. Gibson and J.C. Venter, 2014, Synthetic biology: Construction of a yeast chromosome, in *Nature*, Vol. 509, pp. 168-9, doi: 10.1038/509168a.

In addition to these future problems, let us now consider a current problem with contemporary implications:

Bioethics of ageing and dying. This problem was mentioned earlier in our conference by Ms Michèle Stanton-Jean⁵. Technologies for prolonging life and merciful death are now available, but under what circumstances should they be used or not used? How far should we go in prolonging life and what role do considerations such as the quality of life and costs play in such considerations? On the other hand, when, if at all, should technology-aided euthanasia be considered? Technologies for organ replacements, cell and gene replacements also fall into the same ethical category.

These are some of the issues to be considered by the Bioethics Programme in the future. It will be interesting to see what the next fifty years may bring, and what role bioethics can play. We can only hope that more importance will be given to bioethics in the use of new technologies for health and the environment. The IGBC will be very interested in working together with the IBC and relevant programmes of UNESCO to consider these issues, and to make relevant recommendations to the member states in particular, and the public in general.



5 *Intra* Michèle Stanton-Jean, pp. 53-56.

The next twenty years

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Looking back twenty years to 1993, it seems almost as though life was rather simple then. We knew that there were some interesting and challenging issues coming out of developments in genetics and human embryology. We saw the rapid progression of the biosciences and we were keen to codify our understanding of ethical approaches to biomedical research. We had a reasonable idea of what we had in view, and were finding ways of handling it. A huge amount of work was being done, not least at UNESCO, which adopted its Universal Declaration on the Human Genome and Human Rights in 1997. Of course, it wasn't really as simple as that, and there was the persistent notion that ethics was struggling – maybe even failing – to keep pace with developments in science. But still, let us enjoy hindsight whilst we can. Because foresight is so much more difficult.



If the past twenty years has been characterized by bioethics applying itself to issues that lie largely in the biomedical sciences, what then for the next twenty years? The simple answer might be 'who knows?'. Science does not follow a straight or linear path, and few of us would gamble on which particular line of research is likely to emerge, or when it might do so. But to abandon ourselves to chance in that way would be to guarantee that we stay well behind the curve. If we have learned anything from the last twenty years, it is surely that science itself must open up discussion of new developments at the earliest possible stage, and that we must orientate ourselves so that we are in the best possible position to engage in and promote discourse on the social and ethical dimensions of emerging science. In this way we can be alert to the risks that might be entailed, but more importantly we can be in a position to direct and harness science in ways that are socially most beneficial.

That is easily said. But whilst what lies behind us might look relatively simple in retrospect, what lies before us is increasingly

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complex. Developments in biotechnology, nanotechnology, neurotechnology and information technology (to name but a few ‘-ologies’) are difficult enough in themselves in terms of understanding and managing their potential future applications. But when they combine and converge in novel ways, they present even greater challenges. Synthetic biology that might generate novel, functional organisms; the application of powerful new informatics systems to expanding databases of whole genome sequences; scanning and imaging technologies; robotics and the development of computer-aided biological systems where biology

and technology begin to merge. These are all with us and developing rapidly. And the point about these developments is not only that they are complex, but that they breach our existing categories – categories of what sits within the life sciences as opposed to the physical sciences, and categories of what is or is not health-related. They also have, from the outset, a global dimension as their contributors and applications are not limited in any way by local, national or regional boundaries.

This complex vision of the progression of science in the coming years can be challenging and daunting. But we must also recognize how essential it will be in helping to address some of the most problematic issues of our time – persistent health inequalities; the adverse effects of climate change; and the increasing prevalence of disorders such as dementia, obesity and poor mental health.



This is an exciting period, then, and one that will bring some immense opportunities as well as challenges. It has many implications for all of us, but there are four things in particular that we need carefully to consider, whether as concerned individuals, as UNESCO or other relevant bodies, or a society as a whole.

These are, firstly, that we must work across disciplines and across sectors to gain insight into what is coming; to evaluate what is involved and what is at stake; and to consider what might be needed

to support, protect or respond to these developments. This means working not only across technical disciplines, but also ensuring good communication and collaboration between the life sciences, social sciences and humanities, and fully involving civil society.

Secondly, we must be careful not to box in 'bio', as the conjunctions between 'bio' and 'non-bio' are going to be critical. Equally, we should not limit ourselves to thinking only about the medical environment – what is 'medical' has changed, and now extends to predictive and preventive interventions. Moreover, new applications are also relevant in terms of what might be called 'health optimization' or enhancement; and many applications will extend to fields that are not at all health-related, such as in industrial, leisure, environmental and agricultural sectors.

Thirdly, we must continue to promote wide public awareness and discussion. The significance of new technologies is often dependent on the social context in which they emerge. It is essential that a public discourse should be encouraged so that we can understand that context and engage the whole of society in considering their concerns, priorities and responses in respect of developments in bio-related technologies.

And finally, we must continue to work globally – in supporting and helping develop the capacity of all nations to reflect on bioethical issues; in enabling all parts of the world to gain benefits from new scientific and technological developments; and working together to gain common insights and approaches where appropriate. UNESCO is not alone in pursuing this programme of work in bioethics. There are national bioethics advisory bodies, civil society groups, academic and policy groups who will also apply themselves to these challenges. But with its unique international – indeed global – perspective, UNESCO is well placed to carry this agenda forward over the next twenty years.



Concerns for Bioethics in the coming years

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The future prospects for bioethics come from its recent past and its present. Of late, thanks to the leadership of UNESCO, bioethics has managed to detach itself from the image imposed upon it by its origins, which were excessively individualistic and centred primarily on biomedical issues specific to the central countries. Gradually, albeit with highs and lows and variations, new trends in bioethics have set it on a course involving the ethical issues arising from the social injustice and inequality that prevail around the world, particularly in poor peripheral countries, but which are also becoming more and more apparent in wealthy, central countries.

Although not a view unanimously shared around the world, the commitment of bioethics to human rights and human dignity is gradually capturing the attention of academic communities committed to social justice. Nevertheless, community interests that wish to see bioethics more as a means to maintain their preferred *status quo*, are obstacles for continuing to develop this discipline in close collaboration with social justice and human rights. Indeed, corporations of all kinds where economic and political power are concentrated (medico-industrial complexes, dogmatic and other religious structures) undertake actions designed to ideologically dominate the field of bioethics and to resist the growth of trends and approaches that, naturally, call into question their unethical stance. These actions can be seen in different ways, for example, with the introduction by central countries of bioethics qualification

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programmes in peripheral countries (for which the pharmaceutical industry is often covertly responsible) or the imposition of religious dogma as universal ethical truths.

Over the past twenty years, UNESCO has been at the forefront of secular and progressive universal bioethics thinking, via its Declarations and support for study and training programmes and its dissemination of information. The support UNESCO has given the Latin American and Caribbean Bioethics Network over the past ten years has been fundamental for the development of a bioethics movement in harmony with the principles of The Universal Declaration on Bioethics and Human Rights. This movement is now widespread in Latin America and its continuing education courses in clinical and social bioethics as well as in the ethics of research have produced over a thousand graduates. In the next twenty years, bioethics should be on the same wavelength as the following scientific, economic and social developments.



Techno-scientific developments in the life sciences and health, imposed by dominant economic interests, will probably continue at a pace that will continue to exceed society's capacity to ensure that only those of proven benefit and safety for humanity will apply, particularly in the very grey areas of genomics, of bioinformatics replacing the health professional in medical decisions, bio-banks and others. This means a challenge for intergovernmental organizations to develop and reach a consensus along bioethical lines, that can clearly differentiate between good and bad actions, and on mechanisms that can ensure States comply with the ethical norms arrived at in these agreements.

Attention to health today is primarily in the hands of financial markets whose goals are financial gain (private insurance, pharmaceutical industries, corporate interests of the medical profession) and who will continue to classify people according to their earning power and not to their health needs, paying the least possible attention at all levels. Bioethics should ally itself with other disciplines like public health, social medicine and social movements in general to confront the medical-industrial complex, and defend the right to health. The challenge is how to overcome the prevailing inequality in health and make the right to health a reality, while at the same time avoiding an increase in the level of medicalization. Subjects as important as fighting for universal health systems, equal access to essential medication and new technologies of proven effectiveness and safety, will be the paths bioethics will need to travel, allied with other disciplines.

The growth of biomedical research in the service of the pharmaceutical industry will continue, paying as little attention as possible to the ethical norms established by nation States and by professional and patient associations. Given that a large part of biomedical research in middle- and low-income countries is not a priority, the criterion of pertinence should be used in order to evaluate research proposals ethically, and to classify them in order of importance. It is essential that UNESCO continue its work as a driving force in the creation of bioethics committees, of supporting the criteria of priority and pertinence for research proposals as pillars of ethical evaluation, and resolving conflicts of interest, visible and hidden.

The ethics of development is an expanding field due to the chronic difficulties of human, social and economic development around the world, created by the capitalist system of exploitation, which grants privileges to money and the concentration of wealth, without taking into account the quality of life and the well-being of the majority of the world population. Although traditionally bioethics has not paid much attention to this area, it will doubtless be one of the main priority subjects for action in the very near future.

Poverty and hunger continue to be the cause of illness and death around the world, especially among the most vulnerable populations; this situation will continue to call on bioethics not only to denounce exploitation and the social injustices of brutal capitalism, but also as an active discipline to reach agreement on the measures of social responsibility, to look into the causes of inequalities and reduce them.

The environment will continue to suffer, and bioethics must reflect on how it can intervene to promote ethical policies that can help control or lessen the deterioration and sustain life on the planet.

Education in bioethics has been one of UNESCO's most important contributions in this field. In the years to come, this activity will be extended to all levels of teaching, with approaches that show how bioethics deals with the concrete ethical issues facing humanity, and not just theoretical philosophical discussions. UNESCO must continue its leadership in this field in the decades to come.

The quality of UNESCO's continuing leadership in encouraging bioethics to join the defence of human rights and human dignity, guarantees that it will stay on a course that differentiates it from other functional bioethical directions, with respect to maintaining links with the powers that obstruct the path to social justice and equality.



Challenges for bioethics and UNESCO's future agenda

José R. Junges

Philosopher

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Since the creation of the International Bioethics Committee (IBC), based upon universal declarations agreed and adopted by all of the UNESCO Member States, the meeting and partnership between the field of bioethics and UNESCO has produced excellent results. The work, which covers the protection of life and human dignity in the face of scientific progress, serves as a reference for the construction and formulation of human rights. The most significant, certainly, was the Universal Declaration on Bioethics and Human Rights, the result of a political struggle by developing countries, which broadened its scope to provide sanitation, social and environmental systems. For example, it includes social rights such as access to services and resources necessary for good health and the right to a socially and ecologically sustained environment. The rich countries, on the other hand, wanted to restrict the declaration to biomedical topics and protect autonomy in the use of biotechnologies. Ultimately, the Declaration states: 'This Declaration addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions' (Article 1). What then are the emerging challenges that need critical bioethical analysis as well as UNESCO's attention?

What then are the emerging challenges that need critical bioethical analysis as well as UNESCO's attention?

The biotechnological revolution. In recent decades, the biotechnological revolution has focused on genes, based on the decoding of the human genome and the intense research activity that followed. Society had great hopes for these discoveries that might lead to a cure for genetic diseases. At the same time, ethical problems have

arisen concerning the use of the knowledge generated from those findings. UNESCO has grouped these concerns in two documents: the Universal Declaration on Human Genome and Human Rights and the International Declaration on Human Genetic Data.

The gene remains an icon of the new biotechnological revolution, but another focus has emerged in biomedical research as a result of growing developments in neuroscience: the brain. This will offer new prospects for mental health by means of biochemical intervention, instead of the traditional methods of psychotherapy. There is a heated debate between these two baseline trajectories for psychopathologies. At stake is human subjectivity and autonomy. The promise is a definite and more rapid solution to mental suffering. But there remain ethical issues that require further discussion, such as the gradual pathologizing of health and of any suffering or slight disorder found in the manuals targeted at health professionals. It is important to draw attention to dependence of this type of pharmacological solution and the economic interests of multinational pharmaceutical companies involved in the therapeutic proposals. These ethical challenges, that concern chemical applications in neuroscience research, should be discussed and studied by UNESCO's IBC, which should also evaluate their relevance and the importance of formulating a declaration.

Ethical challenges at the frontier. Biotechnological research has faced the limitations of humans, life and matter. Lately, the possibility of improving the human condition through trans- or posthumanism by overcoming its current limitations and weaknesses through technological interventions presents new problems. Society has always relied on human improvement through culture and humanism. Authors of transhuman proposals allege that since humanity failed to follow the educational path, regarded as the natural way, they are therefore proposing artificial means for biotechnological improvement. The debate between the so-called bioconservative authors, who advocate the preservation of human nature, and the transhumanists, who point to a growing technical improvement of human biological and mental conditions, is intense. The main issue is: 'Does the formation and emergence of human subjectivity and autonomy necessarily involve cultural and educational actions as part of their anthropological identity, or are there no essential dimensions of this identity worth preserving?' This debate deserves attention and serious discussion from the UNESCO IBC, which should determine whether it is pertinent to publish such a document or declaration. The possibility of creating artificial life through synthetic biology research is another frontier

of science. Now that a mechanism for synthesizing the necessary chemicals for the production of artificial life has been developed, biology is synthesizing life processes in the laboratory that no longer require them to select and separate them from natural processes as before. With that in mind, it is possible to artificially synthesize life. With the possibility of artificial life, human beings can take the helm of biological evolution with all the consequences that this may imply. Thus, evolution would become one of humanity's ethical tasks. What might this mean for the preservation of biodiversity and its role in ecosystem sustainability? What might the application of artificial life to humans do to their identity? These and other issues are intimately related to bioethics and should be part of its agenda, and therefore, a subject for discussion by UNESCO.

Another science frontier is the domain of matter in nano dimensions, exceeding the traditional limits and manipulation of nanotechnology. This research opens up the prospect of intervention in the human condition and environment, but at the same time carries a number of serious risks because their growth may get out of control, causing possible nano pollution which would mean that nano particles would be stored in the environment and in living organisms. This is an urgent issue that bioethics must include in its agenda for reflection and debate. UNESCO needs to discuss the relevance of formulating a declaration on human rights that also includes this scientific innovation.

Environmental crisis. Environmental sustainability has always been a concern of the UN and, through the organization of conferences, it aims to build consensus among governments' policy measures on environmental protection. Global warming has intensified this crisis, making it difficult to formulate effective interventions on environmental disasters, which are multiplying, affecting huge segments of the population and demanding urgent global political solutions. The latest international environmental conferences have failed to achieve their goals due to powerful economic interests involved in those solutions. Although proposals involve economic and political aspects, there are also important cultural and educational dimensions which should be taken into account to find solutions for the environmental crisis. Even if the subject 'Environment' is the responsibility of other UN agencies, UNESCO could play an important role in this issue by emphasizing educational and cultural aspects of ecological concern. This would help introduce the perspective of environmental justice, awakening ethical and cultural sensitivity to the unfair distribution of access to natural resources and also to the unjust export of environmental

waste to areas inhabited by poor populations, which destroys their environments.

Other emerging ethical challenges. The Alma-Ata Declaration of 1978 by the World Health Organization emphasized the central role of primary care in improving the health of the population. Governments have taken steps to implement public systems of primary health care. Today, we know that a population's health undoubtedly improves when qualified primary care facilities are accessible and culturally embedded. This requirement does not depend on technological sophistication, but more on basic technologies, adequate human resources and health projects built in cultural and community partnership with the population. If bioethics focuses on ethical issues related to human health, it cannot be reduced to moral issues regarding the use of advanced technologies, since it is also concerned with the ethical issues of primary care professionals. Thus, public health should be included in the future agenda of bioethics because health problems and diseases always depend on chronic conditions and not simply on acute events. It requires, in this sense, therapeutic systems of self-care. Health systems must be aware of this situation and bioethics needs to pay closer attention and include it in future debates.

Another emerging issue in the international scenario that deserves attention from bioethics is that of gender equality. International efforts towards the dignity, respect and equality of women are a long way from achieving their goal. Many statements from the UN organizations refer to this goal, but world public opinion is confronted with news about violence against women. This concerns not only women, but anyone characterized by gender difference, such as homosexuals, transsexuals and all sexually diverse individuals. This gender violence profoundly affects human rights and offends human dignity. These violations must be included in the agenda for bioethics and become UNESCO's concern as they largely founded on misogynistic cultural practices that can be overcome with educational policies and cultural change.

The third emerging challenge that must be included in the future agenda of bioethics is the issue of respect for animals. They have always been anthropomorphized, granted status similar to that of people and have therefore been given rights. Nowadays, it has become an issue of great ethical sensitivity. Hence, bioethics and its respective international committee at UNESCO cannot ignore this cultural trend any more. Animals are not just objects of moral respect on the part of human beings, but are henceforth considered as holders of rights.



Future challenges for bioethics: regenerative medicine

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Our human culture is permeated with technology: we live in a ‘technological culture’. This is true for medicine as well. A clear example of new biomedical technology that will impact medicine and society is Regenerative Medicine (RM), which is an interdisciplinary and innovative field of complex interventions focused on biologically repairing, replacing and regenerating damaged or diseased tissues¹. RM uses different approaches, including (stem) cell-based interventions, gene transfer and tissue engineering (TE)². Due to ageing and lifestyle factors, the prevalence of degenerative disease continues to increase. RM interventions in all types of medical areas are being developed, among which are interventions for orthopaedic disorders such as disc degeneration and osteoarthritis, cardiovascular disorders (e.g. heart failure) and (degenerative) neurological disorders.³

Translating RM interventions into clinical trials and society takes time and careful research. For example, today only one orthopaedic RM treatment, specifically the treatment for focal knee

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- 1 A.S. Daar and H.L. Greenwood, 2007, A proposed definition of regenerative medicine in *Journal of Tissue Engineering and Regenerative Medicine*, Vol. 1, pp.179-84.
 - 2 W.J. Li, K. Gollapudi, D. P. Patterson et al, 2010, Cell-based therapies for musculoskeletal repair, in A. Atala, R. Lanza, J. Thomson, R. Nerem (eds) *Foundations of regenerative medicine*, San Diego, Academic Press, Elsevier, pp.478-501.
 - 3 A.S. Daar, H.L. Greenwood, *ibid.*; W.J. Li, K. Gollapudi, D.P. Patterson et al, *ibid.*; K. Masuda, 2008, Biological repair of the degenerated intervertebral disc by the injection of growth factors, in *Euro Spine Journal*, Vol. 17, pp.441-51.

cartilage defects, is approved for market use.⁴ In the meanwhile, stem cell clinics are taking advantage of the hopes and expectations and already offer a variety of unproven stem cell interventions to patients in return for payment. As the amount of (early) clinical studies in this field is expected to rapidly expand in the near future, parallel ethics research is needed to discuss the interwoven scientific and ethical challenges involved in the transfer of these technologies to patients and to society. RM is highly promising but at the same time faces several layers of cross-cutting complexity, not only technological, but also with regard to the introduction into clinical trials, patient care and society.

Ethical issues. The specific characteristics of RM, such as the novelty and complexity of the interventions, the new aim of regeneration, the invasive nature of the procedure, the high scientific and commercial stakes, along with the intense public and political attention devoted to it, give a twist to the classic challenges of research ethics. These characteristics have an impact on the science and ethics of clinical trials, for example with regard to the risk-benefit analysis, designing a trial in terms of outcome measures and control groups, participant selection and informed consent. In addition, RM will also influence society, encompassing both hard impacts (such as costs and risks) and soft impacts (such as changing perceptions on health, disease, ageing and justice).

The inherent uncertainty of first-in-human trials, combined with the technical complexity of RM, make early-phase clinical trials ethically challenging. This is the case in RM trials using biomaterials or scaffolds, but even more for pluripotent stem cell trials. Many safety and ethical issues warrant attention, as a premature trial could jeopardize the safety of participants and impede the development of RM. An issue in translating RM from bench to bedside therefore is to carefully consider which research participants are most appropriate in research. There are at least two issues related to the choice of the

The specific characteristics of Regenerative Medicine give a twist to the classic challenges of research ethics

4 J.D. Harris, R.A. Siston, X. Pan, D.C. Flanigan, 2010, Autologous chondrocyte implantation: a systematic review, in *Journal of Bone & Joint Surgery*, Vol. 92, pp. 2220-33; W.P. Van, 2012, Advanced therapy medicinal products and exemptions to the regulation 1394/2007: how confident can we be? An exploratory analysis, in *Front Pharmacology*, Vol. 3, p. 12.

participants for (early) clinical studies in orthopaedic RM: the uncertainty with respect to the relationship of degeneration and symptoms, and the appropriate stage for intervention. Injecting regenerative compounds into patients with degenerative orthopaedic disorder is, for example, not yet recommended, as controversy exists on the relationship between degenerative changes and patients' clinical symptoms. Furthermore, the most appropriate stage of a degenerative musculoskeletal disorder at which to enrol patients in a clinical study is unclear.

Another issue in translating RM into early clinical studies is the decision as to whether a control group is necessary and, if so, whether this group should receive the standard care or placebo. Placebos for types of procedures other than pills are called sham interventions, which in RM interventions will often involve (minimal) invasive, surgical procedures. As sham will inherently imply physical harms and/or risks, further discussion on the ethics of sham is necessary.

In the area of societal impacts, RM may affect our perception of old age. Some signs and symptoms of musculoskeletal disorders – such as disc degeneration, osteoporosis and osteoarthritis – ‘naturally’ occur in the process of ageing. As the ultimate goal of RM is to treat and prevent degeneration, RM could in one way counteract ageing. However, one could also hold that ageing and the corresponding process of degeneration should not be perceived as a disease, but as a normal process of life. For all anti-ageing interventions the same ethical tension is present: should we accept that ageing is part of life, or should we intervene in the ageing process because it is abnormal? What is new for RM technologies is that for degenerative disorders we could probably intervene in a quite early stage in ageing, thereby preventing ageing. This is a further-reaching form of anti-ageing than slowing ageing as many other products do. If RM is to be applied in other fields than orthopaedics, for example RM for cardiovascular disorders, RM might also be able to extend the human life span, raising additional ethical issues about longevity.

Another societal issue associated with RM is one of justice. Introducing RM in orthopaedics will be a costly project, which neither government nor healthcare insurers are likely to reimburse for each individual patient. This might result in inequalities.

The response. The concerns about the potential risks of RM should come from further developments in the field of RM. Obviously, research will be part of that, and therefore the normative field of research ethics is involved. One may assume that the guidelines that exist within research ethics will be able to answer most of the issues in such research.

In the translational challenges, one could also turn to research ethics as often research will be involved in bringing the RM interventions from bench to bedside. However, we think some additional challenges will arise then. Research ethics, both as an academic discipline and as a field of practice (e.g. research ethics committees and international codes of ethics such as the Declaration of Helsinki), has been well-developed after World War II, but the focus has been on human subjects research. The ethics of so-called complex translational trials has received scant attention. The ‘traditional’ paradigm of clinical research ethics has focused on pharmaceutical trials rather than early phase innovative trials such as in RM and stem cell-based interventions, surgical innovations, medical devices and other (converging) technologies. For innovative technologies, like RM, the traditional ethical benchmarks for conducting clinical research proposed by Emanuel et al.⁵ require refinement. In particular, the decision of when translation into first-in-human studies is justified is challenging, because these complex novel approaches have never been applied in humans before.

For the societal issues involved in RM we believe ethical parallel research is necessary. This kind of ethics research can contribute to sustainable, ethically sound innovation, particularly now the RM field is rapidly growing and several trials and innovations are under way. This position originates from a constructivist view of science and technology, where science, technology, ethics and society ‘co-produce’ each other – rather than the traditional view where science, ethics and society have clearly demarcated roles. ‘Co-production’ means that scientists, clinicians, ethicists, patients and other members in society generate new knowledge, treatments and medical technologies together in a dynamic interaction. This is particularly important for translational medicine: there can be no innovation without social and public support.

Incidentally, the opposite is also true: there can be no innovation without societal cause. It might be stipulated that RM is in itself an example of how technology can also be a response to a societal need, as RM seems to have evolved from a societal development, namely the increasing importance of the liberal ideology in the Western world. Concepts such as autonomy and personal freedom are central values of liberalism, and these values are especially threatened by disease of old age. Degeneration could lead to a decreased mobility and greater dependency on others, limiting individual freedom. This

5 E.J. Emanuel, D. Wendler and C. Grady C, 2000, What makes clinical research ethical?, in *JAMA* Vol. 283, pp. 2701-11.

may have formed an impetus, be it conscious or unconscious, to start developing RM technologies.



RM is a new, innovative field of complex, biologically based interventions that is expected to change medicine radically in the future. It is necessary to ensure that the ultimate aim of these interventions is patients' well-being. RM faces challenges that simultaneously involve widely divergent fields of expertise. In order to guarantee ethically sound innovation, constructive interdisciplinary collaborations and dialogue will be necessary to proactively identify and evaluate the ethics of translational RM; not at the 'further down the line' but now, as the field develops. As science, society and technology are mutually constitutive we argue that all stakeholders should be involved in the societal debate. By taking up their role as actor they can shape the societal impacts and drive responsible innovation in RM.



Assessment of past achievements for the future

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On the basis of a few activities carried out between the 1970s and 1980s, Federico Mayor¹ felt in 1992 that the time had come for UNESCO to establish a coherent Bioethics Programme. Indeed, UNESCO was the only organization of the United Nations system whose mandate drew together all the constituent elements, namely: the sciences, philosophy, culture and education, and which could carry out such a Programme with a multidisciplinary perspective.

But what were the objectives he had intended to assign to the Bioethics Programme? The main aim was to create a programme planned around ethical reflection, in light of the spectacular advances of the health and life sciences, and to consider their repercussions on society; an ethical reflection founded on the basis of universally recognized rights and freedoms and associating all the regions of the world. This initiative was to lead to the construction of a global ethic through the drafting of principles and norms freely accepted by the international community.



At the time, one of the greatest challenges was the Human Genome Project, the decoding of which had already begun and, with it, the issue of the patentability of the living being. So in 1992 and 1993, the initial task, in preparation for the establishment of the International Bioethics Committee (IBC), under the leadership of

1 See *intra*, pp. 47-51.

Mme Noëlle Lenoir,² was to explore the different aspects of progress made in genetics.

The outcome of those first IBC working sessions was the adoption by the General Conference in 1997 of the Universal Declaration on the Human Genome and Human Rights, followed in 2003 by the International Declaration on Human Genetic Data and in 2005 the Universal Declaration on Bioethics and Human Rights.

One of UNESCO's chief accomplishments has been to inscribe bioethics on the international political agenda. Bioethics is no longer a matter merely for specialists and science experts, but one that addresses the *polis*; it concerns the citizen community and is situated, as they used to say in Ancient Greece, *es meson* (meaning 'in the middle'). In 1998, there was an unprecedented event at UNESCO, within the framework of the celebration of the fiftieth anniversary of the Universal Declaration of Human Rights (1948),³ the United Nations General Assembly adopted the Universal Declaration on the Human Genome and Human Rights (UDHGHR). Until then, UNESCO had cooperated with the Inter-Parliamentary Union in order that bioethics be one of the subjects studied by the Inter-Parliamentary Conference.⁴ It had been the same with regard to the cooperation between UNESCO and regional intergovernmental organizations, notably the African Union (at the time called the Organization of African Unity) and the Organization of American States.

But had the objective been achieved to formulate principles and norms adopted by consensus in the field of genetics? The answer is no. One of the avowed aims of the UDHGHR was to prevent the human genome in its natural state from being patented by proclaiming that it was the heritage of humanity and therefore that it should not give rise to any monetary gain.⁵ The matter of patents in this regard does come to the fore every now and then. A recent episode in the United States of America between 2009 and 2013 kept the courts busy at differing levels with many reversals of the situation, following the request of the Myriad Genetics Company to obtain patents. Fortunately, on 13 June 2013, the U.S. Supreme Court ruled that naturally occurring human genes are a product of nature and therefore not patentable: 'genes and the information

2 First Chair of the IBC.

3 United Nations General Assembly, Resolution 53/152 of 9 December 1998.

4 Bioethics and its Implications Worldwide for Human Rights Protection, 93rd Inter-Parliamentary Conference, Madrid, 1995. <http://www.ipu.org/conf-e/93-2.htm>

5 'The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.' Article 1, UDHGHR, and 'The human genome in its natural state shall not give rise to financial gains.' Article 4, loc. cit.

they encode are not patent eligible ... simply because they have been isolated from the surrounding genetic material'.⁶ It should be noted that in its ruling the Supreme Court made reference to the UDHR.



The above example has been given to illustrate the first of the objectives of the Programme, in my view, for the years to come: the permanent consolidation of achievements. It is essential to return to the subjects already dealt with in light of new developments which may pose unprecedented questions, or may show issues in a different light. The positions adopted with regard to stem cells are a case in point and doubtless these should be considered anew because of the hopes they raise, for example in the field of reparative medicine.

The permanent consolidation of achievements

But consolidating achievements does not only mean submitting principles and norms to the test of new findings and innovations. UNESCO's hard work must be continued in order to enable the creation of institutions in all countries of the world, which can become leaders in the field of bioethics research, training and information. Without such constant appropriation by each country in the world of bioethics research, inequalities could become more pronounced in this area between the different groups of countries around the world.

Secondly, UNESCO could anticipate the impact that brain research will doubtless have at a social and individual level. The neurosciences, brain scans and the prototypes of electronic implants are already exploring the complex pathways which will extend our knowledge on the mechanisms of behaviour and, consequently, our capacity to modify them. These issues may well have consequences for rights and freedoms, such as the freedom to end one's life or the right to a private life.

And finally, the Programme could examine the ethical consequences of the expanded use of electronics in medical practice, for example through computers or mobile phones. This is not merely a matter of telemedicine which is spreading out to diverse areas in clinics, from diagnostics to monitoring, but also about the transformations it will bring to the doctor-patient relationship,

6 Supreme Court of the United States of America, No. 12-398, *American Association for Molecular Pathology vs Myriad Genetics*.

notably with regard to managing medical data, the communication of sensitive information, the decision-making procedure or to other elements that come into play in therapeutic relationships.



Today, UNESCO's resources are by no means inexhaustible; tomorrow they will doubtless be reduced still further. So choices have to be made. That is why priority should be given to essential issues, amongst which are those UNESCO is best placed to deal with and those which would not be examined by other institutions. Lastly, let us end with a line by the poet Louis Aragon who might remind us that bioethics is in constant construction by human beings for human beings.⁷

*Nothing ever belongs to man
Neither his strength
Nor his weakness nor his heart*



7 L. Aragon, 1946, *La Diane française*, Paris, Seghers.

Bioethics needs bayonets

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Reviewing the role of UNESCO, and especially the International Bioethics Committee (IBC) in the field of bioethics over the past two decades, I will briefly address three questions: what has been achieved, why UNESCO, and what to do in the next twenty years?

What has been achieved? It is easy to reiterate the long list of unique achievements of the Bioethics Programme: the adoption of several normative instruments, the establishment of the IBC and the Intergovernmental Bioethics Committee (IGBC), the creation of national bioethics committees, the promulgation of the core bioethics curriculum in universities around the world, the setting up of the Global Ethics Observatory, to name but a few. Without UNESCO, these achievements would not be available today. But the major and lasting contribution in my view is that UNESCO has facilitated and promoted the emergence of a new type of bioethics, *viz* global bioethics.

Nowadays, we have entered a new stage in the development of ethics in connection to medicine, health care and life sciences. Initially, and for a long time defined as professional ethics, bioethics was born in the 1970s as a response to the power of medical science and technology. It has rapidly evolved into a strong discipline with a clear conceptual and methodological framework and with the appropriate hardware of a scientific discipline: textbooks, journals, conferences, associations, educational programmes. But this type of bioethics is closely connected to more developed countries that are confronted with scientific advances and technological innovations. It has therefore a limited agenda and scope that is hardly relevant for the majority of the world population living in less developed countries with limited or no access to healthcare, and with no benefits from the progress in science and technology.

The globalization of healthcare and medical research has created a different context for bioethics. The major bioethical issues of today

are no longer concerned with the power of science and technology, but with the power of money. Neoliberal market ideology has created increasing inequalities in health and healthcare. Because welfare safety nets and healthcare systems have been privatized and social protective mechanisms deregulated and minimized, healthcare has become even more inaccessible, and individuals, groups and populations are now more vulnerable than before. The United Nations Development Programme concluded in 1999: 'People everywhere are more vulnerable'.¹ Bioethics is taking into account more and more the effects of globalization, focusing on the forgotten, the invisible and the ignored billions of people who are powerless and voiceless, and lack basic healthcare.

The major contribution of UNESCO over the past two decades is that it has greatly influenced this change in bioethical perspective. Bioethics was already concerned with global change before it was even reflected in the name of the Social and Human Sciences Division. The Bioethics Programme promoted a broader view of bioethics, linking individual, social and environmental concerns, and it therefore articulated the notion of global bioethics, previously proposed by Van Rensselaer Potter but ignored in mainstream bioethics for a long time.² The Programme also put on the agenda different issues and topics such as social responsibility, benefit sharing and protection of future generations, proposing a normative framework for a truly global bioethics that could go beyond the limited perspective of the 'Georgetown mantra'.³

Why UNESCO? In evaluating the achievements of the Bioethics Programme and in reflecting what could be done in the next twenty years, it is imperative to underline the special role of UNESCO in this field of many different players and stakeholders. Firstly, there is no other global platform for bioethics that brings together moral perspectives from all countries on an equal basis (at least in principle). There is also no other global entity that combines standard-setting and practical implementation activities in the field of bioethics. And finally, there is no comparable forum that is connecting science and policy-making. This last feature refers to the IBC. The institutional functioning of this committee within the organization, at the same time as its independent role as expert advisory body, highlights a

1 United Nations Development Programme, 1999, *Human development report 1999*, Oxford, Oxford University Press, p.90.

2 H. ten Have, 2012, Potter's notion of Bioethics, in *Kennedy Institute of Ethics Journal*, Vol. 22(1), pp.59-82.

3 The 'Georgetown mantra' includes the principles of beneficence, non-maleficence, autonomy and justice.

unique aspect of global bioethics. It also demonstrates that bioethics is more than an academic enterprise; it needs to be translated and transferred into practical activities on the ground. The expertise assembled in the IBC reflects this liaison of brains and hands. Finally, UNESCO is also driven by certain values that are utterly relevant for global bioethics. Specifically, its focus on the common heritage of humankind could be better exploited in this field. This focus directs attention to the common good. It expresses the basic idea that humanity needs more than exchanging commodities in a free market, and that humankind can only survive if it cares for global commons. This care can only be accomplished on the basis of pragmatic solidarity and respect for diversity.

What to do in the next twenty years? Future activities should be based on an analysis of the fundamental challenges. The major problems of global bioethics nowadays are related to structural injustices and social inequalities in health and health care. Current international clinical research does not sufficiently contribute to the alleviation of the global health burden and does not help to eliminate structural injustice⁴. Medical anthropologist Paul Farmer concluded that ‘... the fundamental problem of our era [is]: the persistence of readily treatable maladies and the growth of both science and economic inequality’.⁵ The goal of bioethical activities in the global era should therefore be to address global health inequities and to reinsert a social commitment in healthcare, not as a business but as a human engagement.

Against this backdrop there could be three main lines of action for the Bioethics Programme of UNESCO. Firstly, a more vigorous participation in global policy activities showing concern for including bioethics in debates about global health. UNESCO should be present in consultative and deliberative processes such as the current revision of the Declaration of Helsinki, the revision

The goal of bioethical activities in the global era should therefore be to address global health inequities and to reinsert a social commitment in healthcare, not as a business but as a human engagement

4 A. Ganguli Mitra, 2013, A social connection model for international clinical research, in *American Journal of Bioethics*, Vol. 13(3).

5 P. Farmer, 2005, *Pathologies of power. Health, human rights, and the new war on the poor*, Berkeley: University of California Press.

of the Council for International Organizations of Medical Sciences Guidelines, and the initiatives to draft a Framework Convention on Global Health for the post-2015 development agenda (World Health Organization).

Secondly, the Bioethics Programme needs actively to promote the agenda for global justice. Rather than focusing on sophisticated technologies or complex issues, it requires the development of a social bioethics focusing on countering structural injustice, marginalization and exploitation of vulnerable populations. The next generation of bioethical problems has less to do with ‘converging technologies’ but rather with ‘diverging benefits’. Taking global justice as a central focus will imply a critical approach towards the neoliberal model of globalization that is disseminated by other international organizations. Sometimes cooperation with selected and engaged NGOs will be more effective than collaboration with governments. Opportunities should always be provided for giving a voice to ‘bioethics from below’.

Thirdly, it is useful to remind ourselves of an expression that is used in many developing countries: laws are made of paper, bayonets are made of steel. In other words, talking is good but acting is better. The Bioethics Programme should therefore continue its efforts to implement the normative framework of the declarations with practical activities. However, they may be more targeted than in the past, recognising that not all conditions are equally fruitful for the development of bioethics. Highly selective targeting of specific countries should be necessary, also because of budget limitations. But within the selected targets, a broad range of interconnected activities should be employed: fostering functional bioethics committees, stimulating active teaching programmes, encouraging public debate, at the same time monitoring and reporting about progress, so that bioethical country models can be publicized.





Global Bioethics: What for?

20th anniversary of the Bioethics Programme of UNESCO

Through the experiences of each of the authors, specialists from all over the world, men and women who have contributed to the Bioethics Programme of UNESCO, here are thirty articles of four pages each providing us with many accessible definitions of bioethics and its use. This book is just one of the ways in which the Programme is celebrating its twenty years of existence.

The reader will find thought-provoking ideas with regard to philosophical concepts and attributes of bioethics, its normative interest and fields of application, and the challenges it faces.

Authors such as **Daniel Callahan, Michèle Stanton-Jean, Federico Mayor, Juliana González, Michael Kirby, Mary Rawlinson, Henk ten Have** or **Vasil Gluchman** talk of our Programme's history and the benefits it provides and they debate which is the best framework for its future in terms of values, procedures, principles and policies. It is through bioethical discernment, with its complexity, cultural diversity, social differentiation and economic inequality that answers can be found, with our feet planted in local history but our sights set on the holistic horizon.



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