

## **THE UNIVERSAL DECLARATION ON BIOETHICS AND HUMAN RIGHTS: bioethics, a civilising utopia in the age of globalisation?**

**Christian Byk, judge, secretary general, International association of law, ethics and science, member French national commission for Unesco**

### **Summary**

By adopting the Universal Declaration on Bioethics and Human Rights in October 2005, the General Conference of UNESCO, the United Nations Organisation in charge of science and culture, showed the ability of this “big thing”, composed of 191 member states, to bring to a conclusion in barely two years the drawing up of a far-reaching text on a sensitive subject both for citizens and for states.

Although it is real and has brought increased esteem to an organisation that used to be criticised and that the United States, a sign of the times, decided to join in 2005, this « tour de force » should not, however, conceal the limited legal scope of the text adopted.

Although its style is clear but far from lyrical, it is mainly the content of the text and the measures that aim to guarantee its effectiveness that fall short.

Indeed the text tackles no contentious issues. That is understandable for human cloning which is the subject of a controversial Declaration adopted by the UNO in 2004. It is less so for biomedical research, which is, however, already the subject of international rules drawn up by the medical authorities (World Medical Association, International Council of Medical Organisations), or organ transplants, as the World Health Organisation (WHO) got the states to agree in 1991 to a series of ethical principles which are to be respected.

Let there be no mistake: this **substantial weakness** is **conscious** and, in a way, wanted by the original writers of the text. By taking up the challenge that the 32<sup>nd</sup> General conference had entrusted to them in 2003, the writers understood that the importance of the text would be less in the apparent illusion of proposing ethical and legal solutions at world level than in the fact of integrating life sciences into global thinking which takes into account cultural diversity and economic and social differences.

The second main cause for concern in the text is the weakness of the procedures that aim to ensure a follow-up of the implementation of the principles set out by the Declaration. Unlike the Universal Declaration on the Human Genome and Human Rights which contains an innovative mechanism for follow-up, the present Declaration, under pressure from the states, depends on an approach which is essentially based on (the states’) good will.

This being so, the first disappointment could be turned into a more positive situation if the various bodies to whom the text is addressed, principally the states but also the scientists of UNESCO itself, took advantage of the Declaration’s dynamics and took over the area of international cooperation with their actions as the Declaration encourages them to do.

In this way the Universal Declaration on Bioethics and Human Rights, the first text of its kind with a universal vocation, will not remain unenforced but will add its own stone to the construction of a more balanced global world.

### **Bioethics and the founding values of international order**

International texts are often regarded as contributing little on a legal level by the countries which, before the texts were adopted, already had specific legislation about the subject under

consideration. At best, if these countries have defended their interests well, the international text reflects and reinforces the legal solution that they had adopted in their own law. At the worst, and this is what they fear the most in the negotiation process, the solution retained will be an unsound compromise between several diverging legal approaches.

These states do not think, or only rather condescendingly, of the fact that this future international instrument also aims to serve as a reference, a guide, to the states which have not yet drawn up legislation.

This extension of the legal order to the fallow land of the law of emerging states, thanks to the strength of a dynamic model, is already in itself a positive element in international law.

With the Universal Declaration on Bioethics, a **reversal of perspective** seems to have been added.

The substance of the international text is no longer only a factor in the promotion of internal law; it is also an affirmation that life sciences are attached to universally recognised principles, human rights, and that these founding values of international order constitute, notwithstanding the economic or socio-cultural dimension of biomedicine and biotechnology, the heart of the ethical and legal standards which should govern them.

Clearly, this dimension is also found in the scope and proclaimed objectives of the Declaration (A). But it is above all a reading of the stated principles which gives a clear idea of the change. The lively debate which has taken place between countries of the North and countries of the South has given rise, not to a compromise but to a balance between the principles relating to individual rights and the principles concerning collective rights (B).

### **A Ambitious scope and objectives: contributing to the aims of the new international order**

The international dimension of bioethical issues is not new.

In a perception of bioethics as an extension of medical ethics, it is reflected in the declarations and position taken by professional organisations, such as the World Medical Association, or the Council of International Organisations of Biomedical Science (CIOMS), concerned, since the second world war, with renewing links with the historical heritage of universal medical ethics adapted to the present world. This dimension can also be found in the policies of harmonising laws and regulations, mainly in Europe, when the states are concerned about the effects of “biomedical tourism” which can result from too great a disparity of internal law.

But, with the Declaration adopted by UNESCO, another dimension of the « internationalness » of bioethics comes to the fore. **Bioethics** ceases to be simply a “forum” of preoccupations about the risks resulting from the applications of biomedicine and becomes a **catalyst of political objectives**, the promotion of which had previously been done in a variety of international texts (2). In the process, bioethics asserts itself, outside its original field, i.e. biomedical science, and embraces a global dimension unlimited by time, protecting biodiversity as well as future generations, the biosphere and cultural groups (1).

#### **1) Bioethics, a new holistic view of life :**

The philosophy of the Declaration clearly breaks with the tradition of breaking ethical questions resulting from the boom in “new” biomedical technology into sections. Of course, this approach is also pragmatic and “opportunistic”. The fundamental differences that exist over assisted procreation or techniques of genetic engineering made the task entrusted to the director general of UNESCO of drawing up a Universal Declaration of bioethics including

these fields particularly perilous. But the “thematic” approach was not impossible to carry through, at least for certain issues, as biomedical research or organ transplants had already given rise to the adoption of texts with international scope. The writers of the Declaration, therefore, made the careful choice of giving, not from considered technique and practices, but in a more global way, their vision of bioethics.

### **Respect for life is the leitmotiv of this vision**

This is a respect for all forms of life organised around man and by man himself but it is also a dynamic respect for life open to biological and socio-cultural evolution.

#### a) a leitmotiv: respect for life

This will to assert respect for life should not be perceived only as a “reflex” in the face of the risks connected to the use of new biomedical technologies. Resorting to human rights and rebalancing the powers of science for the benefit of patients and citizens is, of course, an important element for “preserving the dignity of the person and the universal and effective respect for human rights and fundamental freedom” (3<sup>rd</sup> point of the preamble). But, the vision of respect for life goes further: involving “the civilised world” even more, it is a question of taking into account “the growing influence that the rapid progress of science and technology has on the idea we have of life and life itself” (2<sup>nd</sup> point).

It is not only what we are but the awareness that we have of it and the social and global organisation that follows that are at stake. Consequently, it is a matter of urgency – but it is an existential urgency – for “the international community to set out universal principles on the basis of which mankind will be able to respond to the growing number of dilemmas and controversies to which science and technology give rise for mankind and the environment” (4<sup>th</sup> point).

The connection thus made between mankind and « his » environment is a visible sign of the conviction acquired – by the emergence of problems raised by the extensive “domestication” of “our” environment – that the planet is a whole and our activities, however useful and necessary they may be, should treat the branch on which they are sitting with care. More precisely, there is the awareness of a chain of possible consequences the effect of which could have a devastating dimension, even if, unlike the nuclear risk, there is not always a visible and traumatic explosion. Therefore the Declaration states that is it “aware that human beings are an integral part of the biosphere and that they have an important role to play by protecting each other and by protecting other forms of life, in particular animals” (11<sup>th</sup> point). This is nothing less than a call to build another Noah’s ark.

The final objectives of the Declaration – the ones which, if carried out, would establish the outcome – certainly go in this direction:

- “safeguarding and defending the interests of present and future generations; and
- emphasising the importance of biodiversity and its preservation as a common preoccupation of mankind” (article 2 VII and VIII).

#### b) a dynamic combining progress and responsibility

Although respect for life in all its forms should guide mankind’s actions with regard to the implementation of science and technologies, this permanent reference of the Declaration is in keeping with a **dynamic process**, “aware of the ability peculiar to human beings to think about their existence and their environment (to) avoid danger and assume their responsibilities” (1<sup>st</sup> point). It is not therefore a purely “conservative” approach that aims to

set human life and the other forms of life in stone but it is a question of emphasising the necessary quest for a balance between “the progress of science and technology, based on the freedom of science and research, and the promotion of the well-being of individuals, families, groups or communities and mankind as a whole” (12<sup>th</sup> point).

In the same way that man and his environment are one, or at least there is continuity between them, the success of this dynamic does not depend solely on technological and scientific factors, even envisaged in a prospective way (10<sup>th</sup> point) but also on a socio-cultural, even political, dimension.

The first words of the preamble remind us of “the ability of human beings to ....sense injustice and ...to display a moral sense” and it is said, almost as a conclusion, “that moral sensitivity and ethical thinking should be an integral part of the process of scientific and technological development”.

Bioethics should be aiming to reconcile “hard” sciences and human sciences, and why not to reconstruct them! Therefore the “Declaration deals with ethical issues raised by medicine, life sciences and associated technologies applied to human beings, taking into account their social, legal and environmental dimensions” (article 1b).

This “global vision” is an essential element in the debate whose objective is “to encourage a multidisciplinary and pluralist dialogue on questions of bioethics between all the interested parties and within society as a whole”. Even more, it takes part in the search for solutions in so far as it is acknowledged “that a person’s identity has biological, psychological, social, cultural and spiritual dimensions” (16<sup>th</sup> point) or that “health does not depend solely on the progress of scientific and technological research, but also on psychosocial and cultural factors (13<sup>th</sup> point).

Through this reasoning, the Declaration not only pronounces “the progress of science and technology as being the source of great benefits for mankind” (12<sup>th</sup> point) but it also makes a necessary association between it and “cultural diversity, source of exchanges, innovation and creativity”, as “mankind’s common heritage” (15<sup>th</sup> point).

#### **a) Bioethics, signaling social transformations ?**

On reading the 10<sup>th</sup> point of the preamble, it is easier to understand the political vision that the Declaration sets out. For UNESCO it is a question of “displaying the universal principles founded on common ethical values in order to guide scientific and technological development as well as social transformations..., taking into account the responsibility of the present generation towards future generations”. In this perspective, “bioethical issues, which must have an international dimension, should be dealt with in their entirety ...”.

##### **a) a civilising utopia**

The reference, made in points 5 to 7, to the international and also regional texts relating to human rights, bioethics and some other more precise themes (biodiversity, health, cultural diversity or the protection of ethnic minorities) shows not only the desire of the Declaration’s writers to integrate it into a large legal corpus connected with human rights but, even more, to make bioethics the dynamic link between the diversity of the goals of these texts and other objectives outside the sphere of the international law of human rights as those encapsulated in the texts elaborated by the World Trade Organisation..

By carving these texts on the same stone, like the French Republic’s motto “liberty, equality, fraternity”, bioethics gives them a common direction aiming to allow “all human beings, without distinction, to benefit from the same high ethical norms in the field of medicine and life science research” (last point of the preamble).

Bioethics, by assuming its vocation to organise the world, promises us mankind reconciled with itself, able to find a balance between freedom of science and well-being of individuals, between scientific progress and socio-cultural factors, between men and other forms of life.

This **civilising utopia** will not fail to provoke criticism. Is it the easy conscience of the states which have all adopted the Declaration (apart from limited reservations expressed about some points)? Or justification of the system of the United Nations and UNESCO in particular, who are nevertheless incapable of finding solutions to situations of conflict or deep differences (as in the area of human cloning or birth control)?

To preserve some hope, however, isn't it enough to be glad of an approach which, without ignoring the moral turpitude of Mankind, replaces it and the institutions which represent it on the path of values?

Although idealistic in its finality, the approach is nonetheless lucid, realistic and pragmatic with regard to the actions that it assumes and encourages.

b) arousing an awareness of every person's social responsibilities

The idea of thinking of bioethics in a global way is, indeed, the only approach which makes it possible to assess the real scope of such and such a technology, to determine the true stakes and to identify prospects early enough for conscious choices to be made.

How can we envisage the reality of physician-assisted procreation without asking questions about its role with regard to all the techniques which ensure regulation of births (including, therefore, contraception and voluntary termination of pregnancy) and without wondering about the place of the child and the family in society?

Similarly, the cost of health expenses should lead to an assessment of the technical and social efficiency of what biomedical technologies contribute.

Finally, the link between the use of certain technologies and our lifestyles (notably in the areas of food and the environment) should not be neglected both to prevent health and environmental risks which are facilitated by the movement of people and animals, and to envisage the human and environmental consequences of changes in our living conditions.

Neither bioethics nor UNESCO's Declaration constitutes, however, a syncretism of all the objectives proposed by the various international measures mentioned in the preamble. It should just try to deal with the issues relevant to its field, "taking into account their social, legal and environmental dimensions", as article 1a emphasises. That is why three general objectives are particularly highlighted: equitable access to advances in medicine, science and technologies, the safeguarding of the interests of present and future generations and the conservation of biodiversity (article 2 VI to VIII).

However, although it is realistic as regards the force of the words, the text neither dictates nor enumerates the measures to be implemented but aims to make the various actors aware of their social responsibilities.

This involves first of all the states, as the text comes from an intergovernmental organisation and the states remain on the international level of major actors of the implementation and credibility of the international commitments, even if they are non-binding. The first target then is to "guide the states in the formulation of their legislation and their policies" (article 2I). But the text does not forget the role of the diversity of the actors every day: "individuals, groups, communities, institutions and societies, public or private" whose decisions or practices may be pertinently guided by the Declaration (articles 1b and 2 II). The declarative

form of the text gives everyone the chance to appropriate its political force. This is the encouragement of multidisciplinary and pluralist dialogue advocated by article 2V. If the Declaration does not impose any form of action, the dialogue to which it invites the actors in the field of bioethics cannot be purely academic. It is the means to couching objectives and above all principles in something concrete.

## **B Political balance between individual rights and collective rights**

**The desire for something concrete**, which is manifest in the Declaration, is both a sign of pragmatism and a mark of political will. The pragmatism comes from the idea that to reach a certain degree of credibility, a Universal Declaration on Bioethics, which furthermore does not try to govern any technique in particular, should cover every situation, every move in the field of bioethics. Hence the phrase that is highlighted as the common denominator of the principles proclaimed: “within the field of application of the present Declaration, those to whom it is addressed should, in the decisions that they make or in the practices that they implement, respect the principles hereinafter”.

**The political will** is what results positively from the confrontation, during negotiations between government experts, between developed countries wishing that the text might exclusively “frame” the human applications of biomedicine and the developing countries wishing that the declaration might not leave outside its scope issues (health, poverty, illiteracy, access to water, control of natural resources, respect for ethnic communities) which are decisive for the well-being and survival of their populations. All of the principles recognised by the Declaration are divided between a reminder of the fundamental principles of bioethics (1) and the insertion of a series of principles relating to the promotion of a collective dimension and the desire, for the benefit of the greatest number and the most underprivileged, to rebalance a state of affairs which accentuates the gap between rich countries and poor (2).

### **c) The fundamental principles of bioethics:**

The Declaration’s text is not particularly imaginative in this respect – but could it be? – It universalises principles, heirs of the history of bioethics, which are recognised in most national or international texts in this field. At the most, for the implementation of these principles, reference is made to certain particular cultural aspects which make it necessary to adapt them to the persons or situations involved.

Based on human dignity and human rights, these principles are: beneficence and non-maleficence, autonomy, protection of vulnerable persons and justice. **This is the bioethical tetralogy.**

However, the lack of reference to the non-patrimoniality of the human body and its parts cannot be considered an oversight.

### **d) respect for dignity and human rights (article 3)**

What can be the meaning of the fact that dignity which is a value and human rights which are a tangible illustration of it are the subject of one article entitled “human dignity and human rights”?

No doubt this is the mark of indivisibility that links dignity and human rights, the latter getting their specific character from this quality which is common and essential to all men and which flourishes in human rights.

It could, however, be objected that putting the two notions on the same level does not take into account the “transcendent” dimension of human dignity whose aura covers, for example, the embryo or stem cells whereas the scope of human rights is more restricted.

Moreover, the particular weakness and vague character of « the obligation fully to respect human dignity and human rights and fundamental freedoms » set out in article 3 a are regrettable.

Doesn't writing something so obvious weaken the scope of the text and its dynamics? The values and rights announced are not a legal restraint and the states are not “deserving” because they observe them. The values and rights are a reference, a guide for behaviour and policies.

Article 3b, which asserts the supremacy of the individual, should be understood not as an expression of a selfish legal absolutism – it would certainly have been better to speak of the supremacy of the human being, following the example of the Oviedo Convention – but as a reminder of a risk: the risk of another totalitarianism based on the incorrect use of science and technology.

Shouldn't this same logic which in the name of dignity encourages a distrust of the state have also led to a distrust of the free play of the market applied to the human body and its parts and to a hope that solidarity between men is not transformed into a new sort of cannibalism?

Couldn't what has been written for the human genome – « in its natural state it cannot give rise to financial gain” (article 4 of the Universal Declaration on the Human Genome and Human Rights) – be transposed for the body and its parts?

It is paradoxical that the states which have been most committed to denouncing the looting of their natural resources by the developed countries should not have deemed it useful to solicit the adoption of a principle condemning the lucrative trading of the human body.

e) beneficence and non-maleficence (article 4):

Although these are classic principles of the bioethical tetralogy, the assertion that it is good to maximise the benefits and reduce to a minimum the risks is still no easier to implement here, even as a simple objective.

Indeed, although in the past these principles could easily guide the doctor in charge of a patient to fix the choice of a treatment, it is not certain that they can be implemented today with the same apparent ease in all circumstances. Research will not always have direct beneficial individual effects. Some individuals or groups will sometimes see their benefit “nibbled away” to the advantage of other groups. The needs of public health may lay a great burden on individuals, a burden which is justified to preserve collective interests (as in the case of a pandemic).

In this way everything becomes a matter of circumstances and the reference to the double principle now functions rather as a form of the principle of precaution in the field of biomedicine.

c) autonomy and its corollaries (articles 5, 6 and 9) :

1° **A key notion** of bioethics and modern medicine, freed from paternalism, **autonomy** is not only a “revenge” of the common law of human rights, which makes all individuals equal subjects in law; it is also the expression of the subject's participation in medical and scientific activity as a citizen or consumer. To express that this is part of a precise social and legal framework, the Declaration explains the two sides of autonomy: on the one hand, faculty and power of decision as regards medical or research interventions and practices which apply to

our person and, on the other hand, responsibility towards others for the possible consequences of our decisions. It is evident for jurists and ethicists that some people's absolute autonomy necessarily supposes the end of freedom for all and therefore of the equality of subjects of law.

It was perhaps necessary to recall this evidence which is necessary for establishing any social contract, and which prevails in a state of law, in so far as the intervention of medicine has sometimes managed to make the participation of some actors of new biomedical techniques anonymous, or even to "reify" it.

Thus the medicalisation of the donation of sperm, which only allows a glimpse of the donors in the form of frozen sperm and so removes the risk of seeing the intrusion of a third party in the family relationship assimilated to a new type of adultery, or the pooling of donated blood for the manufacture of blood derivatives according to industrial processes, have helped to make donors anonymous. By sometimes forbidding even any questioning of their responsibility, the law has consecrated this new sociology. It is not certain that article 5 of the Declaration will put an end to these waivers of common law.

2° **Consent** (article 6) is the natural corollary of the principle of autonomy and the first two paragraphs of this article which are applicable, for the first, to medical interventions and for the second, to scientific research, comply with the definition of informed consent which is usually retained in international texts. However, the third paragraph is particularly interesting in that it recognises that in the case of research carried out on a group of persons or a community, it might be pertinent to request, as well as the consent of each of the members concerned in the group, the authorisation of the community's legal representatives. The implementation of this text which confirms the legitimacy of some groups or communities to protect common interests, is, however, subordinate to the existence of legal representatives (the group must enjoy a certain social recognition) and supposes that the group presents common characteristics related to the research undertaken. From a legal point of view, this text should be able to justify judicial action carried out in the name of a group or a community.

3° **Protection of private life** (article 9) is the second corollary resulting from the principle of autonomy. The text re-asserts the general principle of the use of personal information in compliance with the ends to which the obtaining of it was authorised. It admits exceptions, but does not specify the content, referring instead, to establish the limits, to the respect of international law and in particular the international law of human rights. It is in this perspective that the issue of the use of genetic or biological data collected for research purposes should, if necessary, be resolved to set up a register for the fight against terrorism.

d) protection of vulnerable persons (articles 5, 7 and 8) :

A person's physical or legal condition is of no consequence in relation to the fact that he, like every other person, has rights. It would be particularly paradoxical, perverse even, if human rights did not benefit the people who, because of their vulnerability, find themselves in some way exposed to more frequent or more serious risk of these rights being affected.

It is therefore not in the existence of rights but in the exercising of them that their condition may be distinguished from other people's. To compensate for their inability to exercise their autonomy, it is necessary to plan particular measures to protect their rights and interests.

The need to set up a "law for the legally incompetent" is not in itself a great discovery for the jurist except that in the biomedical field this law, to be effective and fulfil its objective,

presents a certain concrete character. More than in other fields, it takes into account the reality of the situations. Protection is not limited only to people who have legally incompetent status. The reasons justifying the existence of that status do not cover all the situations which could need particular protection when faced with biomedical interventions.

But this protection should not be understood as reducing to nothing the person's autonomy. Since the biomedical decisions that have to be made involve his whole physical and psychological self, and even his private and family life, he should participate, all the more so as his discernment develops and grows or he becomes more lucid. In any case, apart from a refusal of certain interventions, even expressed in simple terms, prior instructions or the designating of a trustworthy person should be taken into account to define their interest to be protected.

This concrete, pragmatic approach also explains why the text of article 8 calls for protection of individuals but also for groups because of their particular vulnerability. The text, however, says nothing about the possibility or not of recognising particular rights for groups as such, since this aspect of the implementation of protection depends on the various national or regional legal systems.

In this respect it could be argued that the Declaration reinforces a classic approach to the recognition of rights by emphasising, as article 7 shows, concrete issues involving persons – and not groups – who are unable to express their consent.

e) justice (articles 10 and 11) :

This principle has to be understood as the affirmation of a concrete rule involving the way of treating people in the field of biomedicine. What has to be emphasised here is that this rule finds its source in a legal principle, the principle of equality, whose scope is no longer limited to equality of rights. The alliance between two attributes of man, dignity and capacity as a subject of law, confers on equality a fundamental character whence comes the ethical and political need for fair treatment, without discrimination.

### **1°equality, justice and equity**

This is the dynamic, positive aspect of the principle of justice: all human beings should be treated fairly and equitably. This idea, already contained in the convention on biomedicine and human rights (article 3: equitable access to health care), is an indication to act in such a way that each person benefits from treatment according to his needs, which implies a certain degree of efficiency in its implementation. This requirement, which appears for the first time in a text of universal scope, will undoubtedly constitute a difficult but crucial point in future relations between industrialised countries and developing countries, severely plagued by health problems.

### **2°non-discrimination and non stigmatisation**

As well as the burden of disease, some people are « pointed at », even treated unfairly because of their illness. Many AIDS sufferers still experience social ostracism. Fear, ignorance, the existence of ethnic, cultural or political conflicts are often the justification for making someone who is suffering from a terrible new disease bear the weight of an illness that frightens and is not controlled. Scientific knowledge, as in the field of genetics, and biomedical techniques can also be misused to classify and grade individuals or groups

according to physical or biological features; finally they can be used as a pretext for policies of “ethnic cleansing” and genocide.

Consequently, “no individual or group should be subjected to discrimination or stigmatisation for any reason whatsoever”. Biomedicine should not fuel racism either “political” or ordinary.

This double aspect of the principle of justice which integrates the taking into account of social and cultural diversity, quite clearly reveals the link between the “classic” principles of bioethics and principles, which appear to be new, with a collective dimension, introduced in the Declaration.

## **2) The emergence of values and collective rights in the field of bioethics:**

The basic principles of bioethics, to which the Declaration gives a universal dimension, have never eluded the collective approach which is necessary for their implementation. There are indeed no principles of bioethics without the existence of a certain effectiveness of biomedicine, which supposes a health system, a drugs industry, the ability to train professionals and, moreover, the ability to ensure lasting funding for these activities.

However, this collective perception until now had only one goal: satisfying needs, recognised as so many individual rights.

With the “new principles” introduced by the Declaration, the collective aspect is no longer a guarantee of the realisation of individual rights; it is the manifestation of a reorientation of values and rights which until now were the basis of bioethics.

On the one hand, diversity becomes a reference to be taken systematically into account in defining policies, making decisions and exercising practices in the biomedical field.

On the other hand, the pursuit of the realisation of individual rights should lead to neither an exaggerated individualism, nor to an anthropocentrism which is dangerous for the respect of life, hence the consecration of the principle of solidarity between men present and to come and the consecration of the principle of responsibility with regard to the environment and the biosphere.

Thus human rights are open to new perspectives so as not to be confined to the defence of human selfishness.

### a) diversity

To give the Nation its cohesion and bring forth free citizens from the hierarchical social statuses that organised society under the *Ancien régime*, the *Déclaration des droits de l'homme et du citoyen* in 1789 voluntarily disregarded geographical, cultural and social particularism, creating a Republic which was one and indivisible, made up of citizens who are equal in law, whose merit alone should prevail to gain access to public functions and honours.

1° The encounter between human rights and life sciences does not aim directly to construct a political society. Its object is to protect the individual and also communities and groups from the risks that the misuse of techno-science can make their integrity and identity run.

Consequently, the importance of diversity must not be overlooked: it is not only a biological factor but also a cultural and historic factor of the development of mankind. In this logic, the recognition of diversity is part of the continuity of the principle of equality with regard to biological and genetic diversity: “All different, all equal”. It is because there is a fundamental equality of all human beings in dignity and in law (article 10 of the Declaration) that no individual or group should be the object of discrimination or stigmatisation (article 11). And to prevent all discrimination the cultural dimension of identity cannot be ignored (article 12).

2° However, although bioethics, linked with human rights, fulfils a function of protecting the identity both individual and collective of human beings, it also contributes to the debate on choices, values and policies. In this respect, cultural diversity and pluralism are two essential elements for making the bioethical debate an authentic study of the relations between science, ethics and society – hence the importance of its multidisciplinary character – and giving it a certain social legitimacy, in particular with regard to the role played by ethics committees.

Thus, taking into account the importance of cultural diversity and pluralism gives respect for dignity and the rights of others its fullness. It follows, without any contradiction at all, that pluralism and cultural diversity “should not be put forward to damage human dignity, human rights and fundamental liberty or the principles mentioned in the present Declaration, nor to limit its scope” (article 12 *in fine*). To remove all risk of autonomy of bioethics, the Declaration explains that bioethics should not be conceived as a “global” ethic which would have all cultures living together in a general relativism denying the universal and political scope of the human rights message. Bioethics’ international triumph does not open the way to post-humanism relegating human rights to the background in favour of a community spirit organised on a world scale.

#### b) solidarity and responsibility

The place of the concept of solidarity is not strictly speaking new in international texts about social rights, whose collective and economic dimension is obvious. It was, however, up till now still rather limited in texts concerning bioethics which essentially put forward an individualistic approach to human rights aiming to allow the patient to regain his autonomy vis-à-vis the doctor. The European Convention on Biomedicine and Human Rights (1997) nevertheless includes an article 3 on equitable access to health care. But it is above all in the context of the work done by UNESCO on the relation between human rights and the human genome that the reference to solidarity has been developed. The Universal Declaration on Human Rights and the Human Genome (1997) includes a whole section devoted to “solidarity and international cooperation” and the International Declaration on the Protection of Genetic Data (2003) plans provision for the circulation of data and knowledge and the sharing of benefits.

The present Declaration only extends the scope of the principle of solidarity to all bioethical activities – which is already in itself a considerable event. It also gives this solidarity which, because it applies to present men and to future generations, to human life and to the environment, has become multifaceted a single, moral and political justification: social responsibility.

This clearly asserts that science and medicine, because of their consequences on life, cannot follow the example of culture and be objects of absolute freedom.

#### 1° solidarity with regard to men, and particularly developing countries

As a general principle of ethics as well as a rule of proof of good management of social interests, solidarity is asserted unemphatically, even without enthusiasm because the term “encouragement” used about it can seem feeble given the urgency of humanitarian situations. But the Declaration is lucid and serves a useful purpose by linking solidarity between human beings and international cooperation (article 13).

It refers to the key notion of social responsibility of which it declines the contours with regard to health, extended to social development (article 14).

It is a reminder that solidarity is a commitment on the part of everybody, a “fundamental objective” of governments in relation to their people (the countries of the South, just like the countries of the North, should feel concerned) but also of “all sectors of society” (article 14a). It is a call for a general mobilisation to promote health and social development because “the right to enjoy the best state of health that he can attain constitutes one of the human being’s fundamental rights, without distinction of race, religion, political opinions or economic or social situation” (article 14b).

And to illustrate the priorities that the progress of science and technology should promote, the Declaration highlights the situations which, with regard to the possibilities offered by this progress, remain the most distressing: access to quality care and essential drugs, access to water, improvement of living conditions and the environment, elimination of marginalisation and exclusion, reduction of poverty and illiteracy (article 14 b i to v).

Reading this painful list of woes, some people will no doubt want to paraphrase this admission of a Prime Minister and say that « bioethics cannot take on all the misery of the World”. It is however, significant that it takes its share and reconciles objective and reality. In this regard, the text of the Declaration opens up an interesting avenue. The reminder of the objectives alternates with some suggestions about the acts of solidarity to carry out. Thus, while asserting the principle of sharing benefits resulting from research and its applications for the benefit of society as a whole and the developing countries within the international community, article 15 indicates the forms that this sharing could take.

It is a case of reinforcing what exists both on the level of infrastructures for health and research, their personnel and the concrete means, notably in drugs, new products and installations designed to provide lasting and appropriate aid to persons and groups who have participated in the research but also indirectly to the whole of the population for whom quality services are still lacking (art 15 a i to vii).

The message about the balance to keep is not one-sided. It is also addressed to those who are likely to benefit from this provision and to their governments. Article 15b, by emphasising that “the benefits should not constitute inappropriate incentives to participate in research”, may also be interpreted as a denunciation of the passiveness of some governments in drawing up public health policies over the long term and in opting for solutions which would have access to care for the greatest number depending on participation in international research projects. “Research revenue” would be as harmful to the health of populations as “oil revenue” is to their development.

## 2° responsibility to future generations

This is not a case of bequeathing a better world to our descendents. The sad memory of the totalitarianism which, during the 20<sup>th</sup> century, sacrificed the present generations to the search, with short-lived success, for the happiness of future generations does not make it possible to think in this way. So taking into account the interest of future generations is seen in a less ambitious way: not guaranteeing them a society of well-being but simply protecting them from the harmful effects of life sciences. The text of article 16, however, remains careful in defining the contents of this protection, being content to give as an example the notion of “genetic constitution”, saying that it should be included in this protection. This is a reference to the Universal Declaration on the Human Genome and Human Rights adopted by UNESCO in 1997, as this text forbids reproductive cloning and practices contrary to human dignity. Moreover, to define the notion of future generations and of the needs and interests to safeguard, one could usefully refer to the Declaration adopted in the same year by UNESCO about the responsibilities of the present generations to the futures ones.

Among the principles engaging the responsibility of the present generations, the following principles are more particularly in relation with life sciences: freedom of choice, maintenance of the perpetuation of mankind and the preservation of life on earth, protection of the environment, human genome and biodiversity, non-discrimination.

As can be seen, the notion of protection of future generations is largely linked to the notion of protection of the environment.

### 3° responsibility with regard to the environment and the biosphere

This idea which appeared in 1972 has kept developing since then in the great international texts relating to the protection of the environment and biodiversity.

Article 17 of the Declaration summarises this evolution.

It takes up the idea of a balance to be found between all forms of life: this is the reference to the interaction between human beings and other forms of life.

It is an implicit reminder that biological and genetic resources are part of mankind's common heritage and that it is consequently necessary to manage access to them appropriately, i.e. according to their usefulness and without discrimination.

It emphasises, finally, that faced with the risks of reckless technical and economic exploitation of these resources, traditional knowledge and human beings as a whole are likely to play an eminent role in the protection of the environment, the biosphere and biodiversity.

For all that, was it necessary to introduce such an article in a text which is essentially destined to deal with the ethics of biomedical techniques which have appeared since the 1960s?

The answer is certainly negative if the text is perceived as encompassing under the term of bioethics only the questions relating to the growing place of life sciences in the organisation of our society.

It may be positive if we consider that, centred on the questions that involve medicine and human life, this text cannot ignore the overall perspective in which life sciences have their place, and more particularly the law which is devoted to them. In this logic, this article should be perceived as a necessary reference to a more general preoccupation, to a legal corpus which is different but complementary. It is a bridge made all the more indispensable that the present Declaration has chosen not to govern each of the biomedical techniques but to present itself as a text of dynamic references destined to inspire the actors who are responsible for the implementation or the regulation of these practices.

### **A dynamic of principles born of the contradiction of interests:**

Is this fusion – confusion, some will think – between a biomedical approach and a social and environmental, even alternative, approach to bioethics so surprising? By “inventing” the word bioethics, didn't Ressler von Potter intend to make man aware of his responsibilities in the face of the planet's exhausted resources and the environmental imbalances resulting from human industrial activity? Likewise, didn't the important role played by theologians and moralists in the conceptualisation and the implementation of the principles of bioethics offer the guarantee that, from the start, the spirit of solidarity and justice would be an element of essential cohesion of the principles of bioethics?

From a socio-cultural point of view, what sense can be given to bioethics, apart from the protection of individuals and the human species against the possible misuses of science, if, instead of maintaining man in the making of history and culture, it contributes with technology to legitimising the idea of a human being reduced to his biology or his genome?

Lastly, from a geopolitical point of view, wasn't it necessary, when unable to resolve all the

unhappiness of the world, to open for the suffering of the most disadvantaged countries a way of political expression which would be acceptable to everyone and to give them a place to build in the order of things in the world to come?

Only UNESCO could by its mandate accomplish this infinitely delicate task.

The mysterious alchemy of international negotiations thus bequeaths to the universal community a Declaration which is “surprising” because of its apparently fragile balance. It will find voice and strength, like the wheel, only as it advances. Hence the importance of the provisions affecting the implementation of the principles and the promotion of the Declaration.