









LAUNCHING EVENT AND SUBMIT SEMINAR







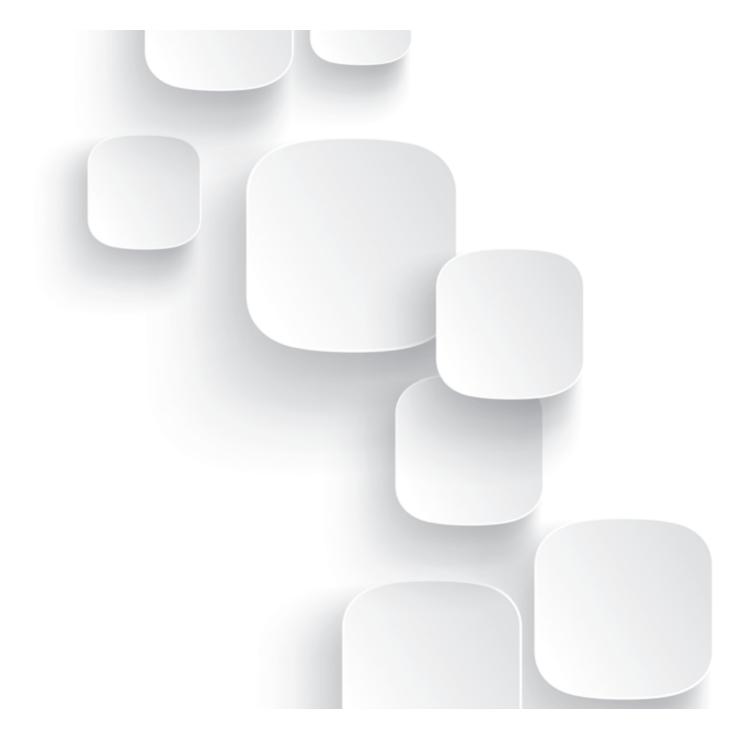
# MEXICO 2014: WORLD BIOETHICS VENUE

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# **PRESENTATION**

As well as we have clear the concept of globalization of the economy, the markets or the networks of communication and information, our response towards others and to the vital conjunction that comprises the universe, calls us not only individually but collectively as well. For this matter, the tool is bioethics.

Our common ethical responsibility must be rooted in culture, scientific knowledge, citizen awareness, and a the global perspective, taking in account our independence in many ways, which includes; equality to all social groups, all knowledge expressions, and all nations and continents that exist today.

In the health field, this assumption is particularly essential since the protection of human life demands preserving the environment where it occurs, and that without doubt is everyone's task.

Today it is urgent that the vision and ethical attitude of individuals, societies and cultures, no matter how dissimilar they are, universally prevails as the first critical reflection of all human endeavors.

From this inclusive perspective, which requires looking at the world in a secular, free, and universal position, is that will take place next year 2014, two events of extraordinary importance: the 10th Global Summit of Bioethics and the 12th World Congress of Bioethics, both to be held in June, in the Historic Center of Mexico City.

This notebook is the summary of the shared reflections made at the launching event that took place in the Secretary of Health, august 19 2013, as well as the considerations made in the Analysis Seminar that took place the next day, with the expectative of the accomplishments for this two world events.



# MEXICO AND THE INTERNATIONAL CONTEXT OF BIOETHICS

#### Manuel H. Ruiz de Chavez\*

These large-scale global events are tremendously important: not only in terms of their academic and scientific value, or in the importance of examining public policies involved in the convergent disciplines of bioethics, but because they go to the core of the preservation of life and the environment that makes life possible.

Since the beginning of this century, discussions have focused on a key issue of our time: the globalization of ethics. While not strictly an original or a new idea – it has been the subject of debate since antiquity, and nineteenth and twentieth-century thinkers and philosophers of course have also reflected on it – I believe that now is the time to fully engage with it.

To some people it may sound antithetical or nonsensical to talk about the globalization of ethics, since it is conceived as a free, independent, responsible and autonomous issue, and as such, some people occasionally suggest that there can be as many ethical visions as there are individuals, social groups, nations and cultures. However, especially

in our globalized context, I consider it important to see ethics as an essential foundation, where respect is related to a responsibility toward life with and for others. In medicine, of course, ethics has always been a bedrock, an unswerving principle.

Just as we have a clear notion about the globalization of the economy or the market, our response to others and toward our surroundings which shape our habitat calls for our shared ethical responsibility which must be rooted in general culture, from a global perspective. Hence we can no longer postpone making the vision and ethical attitude of individuals, societies and cultures, however dissimilar they may be, the universal criterion for reflection on human endeavor. What we need, therefore, is to compile a set of ethical minimums with a universal scope. It will then be essential to rethink ethics and put them into practice, from the fundamental perspective outlined by bioethics, in order to regulate and to resolve conflicts that arise from the development and application of life sciences, as well as in medical practice and research, which can affect life on the planet, both now and for future generations.

<sup>\*</sup> President Council of the National Commission of Bioethics.

#### MEXICO AND THE INTERNATIONAL CONTEXT OF BIOETHICS. MANUEL H. RUIZ DE CHAVEZ

And, from this plural but inclusive position, which requires us to view the world from a secular, free and universal perspective, 2014 will be the year of two enormously important events: the **10th Global Summit of Bioethics** and the **12th World Bioethics Congress**, both of which will be held from 22 to 28 June in the Historic Center of Mexico City.

The **Summit** is a meeting promoted by the Assembly of National Ethics/Bioethics Committees from World Health Organization member countries; it is organized jointly with the WHO's Permanent Secretariat and, on this occasion, also by Mexico's National Bioethics Commission. The **Summit** convenes over one hundred countries from all across the world, as well as numerous representatives from other international organizations. It was first held in the United States in 1992 and since then it has been held every two years, so far nine times in various countries around the world. In 2014, Mexico will be hosting the **Summit** for the first time; the only previous time it was held in Latin America was in Brazil, more than ten years' ago.

The **Global Summit** arose from the need for a forum that would permit a discussion and analysis of the implications of science and technology, and to consider bioethics as

an essential input in the creation of public policies on a global, national and regional scale. It also examines the performance, scope and perspectives of the National Ethics/Bioethics Committees, and this critical and convergent approach represents a unique aspect of the forum.

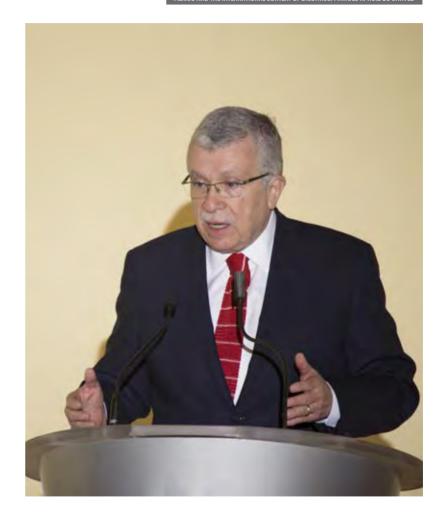
The **World Bioethics Congress**, for its part, is one of the highest-level academic meetings for disseminating news about findings and new theoretical perspectives on ethical questions resulting from progress and the potential consequences of science and technology on life – not only human life but also as regards safeguarding the environment as a whole. This event is organized by the International Association of Bioethics (IAB), a global organization with a network of experts from around the world.

This event has been organized biennially since 1992, and eleven have taken place so far at various venues around the world. The next **Congress**, the twelfth, will be the first to be held in Mexico, meaning that it will be returning to the American continent for the first time in over ten years. The **Congress** traditionally takes place immediately after the **Summit**.

In preparation for these two forums, today we have invited to this launch – presided by Dr. Mercedes Juan, Secretary of Health, for whose unstinting support I am deeply grateful – high-ranking representatives of institutions whose backing and help have been essential to our work: Dr. Francisco Bolívar Zapata, Coordinator of Science, Technology and Innovation at the Presidential Office; Dr. José Narro Robles, Rector of the National Autonomous University of Mexico (UNAM); Dr. Elías Micha Zaga – in representation of Dr. Enrique Cabrera Mendoza, Director General of the National Council of Science and Technology (CONACYT), as well as the distinguished judge of the Supreme Court of Justice, Dr. José Ramón Cossío Díaz.

I would like to thank everyone for being here today, and particularly our distinguished guests: I respectfully request them to share with us a few words before we make our official launch declaration.

In addition to this launch, a Seminar will take place in order to address some of the most salient topics in the field of bioethics, particularly those with most relevance for Mexico. These talks will be given by some of the most eminent specialists and professionals working in bioethics.





# THE 10TH GLOBAL SUMMIT AND THE 12TH WORLD CONGRESS OF BIOETHICS

# Rüdiger Krech\*

Thank you for inviting me to address the participants of the launch ceremony of the tenth Global Summit of National Ethics Committees.

The last Global Summit of National Ethics Committees was held in September 2012 in Cartago, Tunisia, which brought about a common understanding on ethical issues related to biobanking, infectious diseases, organ, cell and tissue transplantation, as well as issues in relation to the functioning, and oversight of Research Ethics Committees.

The Global Summit brings together National Ethics Committees, Commissions or advisory bodies from around the world to share Country experiences in relation to the ethical challenges around public health policies to debate on ethical issues of common global interest, and to contribute to consensus building on ethics issues of public health and health research.

The first such meeting was held in 1996, and since then, the National Ethics Committees have held regular biannual meetings. The number of National Ethics Committees that participate in this event has been steadily growing with an increasing participation of low and middle income countries. We hope that we will continue this path in the Mexico Summit.

Of course, as we saw in Tunisia, the Summit offers a place for regional discussions and activities and it also offers a marketplace for sharing of ongoing activities in the different National Ethics Committees and facilitates interaction between participants.

The main importance of the Global Summit is however not only to have a forum for exchange on ethical issues, the main added value for me is that the Summit focuses on ethical issues that no Country alone could address by themselves only. The themes addressed at the Summit all require a global approach. Therefore, the most important

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#### THE 10TH GLOBAL SUMMIT AND THE 12TH WORLD CONGRESS OF BIOETHICS. RÜDIGER KRECH

work is taking place between the Tenth Summit Meetings: working groups related to the ethical issues to be discussed in Mexico will review latest evidence, identify the particular issues related to the topic, and review the state of the art of the related ethical debate in Countries. This builds the basis for intense debate during the Summit in Mexico City in order to identify common needs.

The preparation for the Mexico's Summit is in full swing, and it is now that National Ethics Committees will need to identify the pertinent ethical issues of global concern that they wish to discuss at the meeting next year. It seems to me that there is still some unfinished business, such as on the issue of biobanking, but we will conduct a consultation with National Ethics Committees on their global priorities and we shall establish an advisory group that will review the outcomes and identify recommendations to the Secretariat.

As has often happened in the past, the Global Summit is taking place back to back with the International Bioethics Congress. The Bioethics Congress has a varied agenda, and a much broader agenda, it encompasses a strong theoretical framework, and it's strong on academics.

The Global Summit, on the other hand, discusses the practical application of issues that are related to human health and has a strong policy framework. This is a good complement of interrelated activities, and I hope that, as usual, there is crossed fertilization of ideas, exchange of experts and there exists the possibility of each to learn from the other.





# THE 12TH WORLD COGRESS OF BIOETHICS

## Angus Dawson\*

The International Association of Bioethics IAB) is committed to developing bioethics across the world, and because of this we have held congresses on almost every continent. The only two where we have not are Africa and Antarctica. I doubt we will ever hold one in Antarctica, but hopefully in the future we might hold one in Africa. The way a Congress is organized is that the IAB works with the national body that has volunteered to put forward a proposal to host the congress. However, it is for the national organization to present and define how the Congress will be conducted. It is an excellent opportunity to express interesting ideas and engage in discussions that are going on here in a national or a regional context and present them to the world. Attending a Congress is also an opportunity to think about how organizations and universities, NGOs, and anybody interested in bioethics can establish new links and perhaps work together more in the future.

Another very important aspect of the IAB Congress is the opportunity to host social events, so that people can talk to each other in a more relaxed atmosphere, and this is also an opportunity, of course, to think about tourism and benefits to the local city and the country that are hosting the particular event.

I would like to just say something very quickly about what bioethics is. I could go on and on about this, and there is lots of interesting discussion in the literature about what bioethics is. So, I won't bore you too much. What 'bioethics' is, is open to dispute, or open to argument. But the key idea is to see that bio-comes from the idea of life and ethics is about our conduct and how we behave towards each other. It is about the character or dispositions that we have in our human interactions and relations with the environment and with each other. The focus on bio- is important because I would want to argue that bioethics is much broader than just medical ethics. So it is not just about the Hippocratic Oath, it is just not just about the relationship between doctors and patients, although they are of course they are an important part of it. Bioethics is much broader than this and includes issues which are much closer to my own heart relating to public health and research ethics, global ethics, animal ethics, and also parts of environmental ethics. So if we are talking

<sup>\*</sup> Deputy Coordinator of the International Association of Bioethics.

#### THE 12TH WORLD COGRESS OF BIOETHICS. ANGUS DAWSON

about poverty and about food and nutrition issues, then these are considerations that ought to be part of bioethics.

I'll just say a little bit on the congress theme itself to end. Bioethics in a globalized world, science, society and the individual is an excellent focus as a theme for an international congress. This is because we have represented in that theme the different levels, the different issues that are important when thinking about bioethics in the broad way that I suggested we ought to. This is because we don't just have concerns about global health, and inequalities, nutrition and poverty, and so on. We also have issues relating to globalization, the way that so many of the policies are conducted now or influenced by factors at the global level. This is clearly visible in relation to the agricultural, food manufacture and retail and pharmaceutical industries. But also things like climate change. If one country wants to do something about climate change, there isn't much they can do, without being involved in trying to influence other countries to act. Action has to occur at a much broader level than just a focus on an individual country.

This Congress, like previous congresses, will encourage discussion and debate, friendship, intellectual exchanges. I very much echo the message that you just heard from

the representatives from the WHO, in relation to the global bioethics commissions and committees, the idea that the Congress allows us to work together to bring the theoretical and the practical together.

It just remains for me to thank once again our hosts and to all those in Mexico who are going to work very hard in the next few months. We know that this will require a great deal of effort, but we know that it will be all worthwhile and it will be conducted with the fantastic spirit that I've already witnessed in our previous discussions and since I arrived here in Mexico a few days ago. This is my first visit to Mexico, but I very much look forward to being back here soon in June next year. Thank you very much.





# PERSPECTIVES FOR MEXICO

# Elias Micha Zaga\*

Mexico hosted a UNESCO bioethics congress in 2004. Now, with the 10th Global Summit of National Ethics/Bioethics Committees and the 12th World Bioethics Congress, the country is once again the venue for these forums, events where experts in the field can analyze and reflect on bioethics – a discipline that in the 1970s was referred to as the science of survival, since it arose as a result of and in reaction to fast-paced changes in various aspects of society at that time. For example, the post-war human rights paradigm and the civil rights movement in the United States, both related in different ways to medicine and health.

This was also an era of justice problems in relation to the right to universal protection and access to health services. There was a boom in scientific and technological development and moral challenges arose from biotechnological discoveries, with their implications for environmental preservation and the wellbeing and survival of human kind.

Many things have certainly happened since then, and there is sure to be an intense and fruitful debate on each of the discussion in the events to come. Dr. Ruy Pérez Tamayo, many years ago now, remarked that bioethics must continue to come up with solutions for the changing world in which we live, precisely in order to ensure survival and to improve the quality of life of humans and other living beings with whom we share this planet. With this he laid out, in a broad sense, the task facing bioethics and the challenges which lie at the heart of the work that will be carried out at the Summit and the Congress.

Today we are gathered in public for the meeting of the National Bioethics Committees, which have travelled a long and sometimes windy road to create platforms for reflection and decision-making, on this vital issue for society, and for the upcoming World Bioethics Congress.

National Bioethics Committees play an important role through their interventions in healthcare to push for health services and medical research for humans that respect dignity and human rights. These Committees also constitute the conscience of the researcher, play a significant role in interdisciplinary and multisectoral education, and form an essential part of the institutional awareness of bioethics.

<sup>\*</sup> Head of Regional Development, CONACYT.

#### PERSPECTIVES FOR MEXICO. ELIAS MICHA ZAGA

As such, the National Bioethics Committee is a strategic body that promotes the development of this multidisciplinary field and a space for dialog in the search for consensuses and agreements that direct the development of science, technology and innovation in the area of health and life itself. We know that much of the work carried out by the National Bioethics Committees has passed through processes of discussion and negotiation, frequently creating disparate views and involving a wide range of interests.

The Summit will surely bear witness to the work undertaken by many governments and consolidate the leadership of the World Health Organization as the international body at the forefront of efforts to create a public policy on this issue that has a global reach and great importance for the present and future of humanity.

The Summit and the Congress are of special interest for CONACYT, as Mexico's lead institution for science, technology and innovation; the various topics to be addressed at these international events, such as the bioethical approach to scientific development and the promotion of ethical guidelines in every scientific process, are directly linked to the institution's core mission. CONACYT has therefore supported the Summit and the

Congress, within the framework of our responsibility and our interest in stimulating reflection on these extremely important issues.

The fact that these events are being held in Mexico will allow us, among other things, to have a space in which to evaluate the operation, integration and consolidation of the various Bioethics Committees in each of the participating countries. We can all learn from the experience from other parts of the world in order to construct an institutional framework that evaluates, comments on, directs, supports and decides the task of institutional research, preserving the integrity of people and life in general.

According to figures released just a few months ago, Mexico now has 1,550 Bioethics Committees registered at healthcare sector institutions. This has meant that decisions to approve research areas, support resulting projects, as well as the institutional processes to provide a service to the population, are taken on the basis of criteria that are impartial and respect people's rights, over and above economic, ideological or religious interests. The road has not been easy. It has required great effort and willingness and a capacity for dialog and negotiation so that, despite the risks, we can picture a world that is transformed to offer a better life.

We are living in the midst of a period of seismic changes which also affect the practice of medicine. The so-called structural reform of the sector has disrupted the rules of the game laid down by the various actors: regulatory bodies, financial institutions, service providers, the 'medical-industrial' complex, healthcare personnel and, of course, the population who use or benefit from the services. Also, the scientific-technological revolution offers a horizon of hitherto unknown possibilities for therapy and healthcare.

Many serious challenges will be addressed at the sessions of the Summit and during the work carried out at the Congress: assisted human reproduction; ethics in research and use of technology; ethics, health and public policies; social responsibility; start and end-of-life dilemmas; global justice; environmental ethics; the human genome; the donation and transplant of organs and tissues; and genetically modified organisms, among others.

These are all doubtlessly issues to be considered in the public policy that will be promoted by the current government. CONACYT has a commitment to Mexico to ensure that the scientific community makes progress ethically, ecologically and safely, and enforces compliance in these areas during the development of projects. Care must to be taken in order to respect applicable legislation on ecology, protection for biosecurity and biodiversity, as well as to comply with conventions and protocols on ethics applied to research. Peer reviews and rigorous, confidential processes are a constant feature of mechanisms for assigning CONACYT's resources.

It is an obligation to strike a balance that makes it possible to place Mexico at the forefront of research and at the same time respect and safeguard the rights of people and institutions, identifying limits between the individual and the collective, the personal and the institutional. We are confident that the Summit and the Congress will help us in this regard.

We are aware of the prestige of the International Association of Bioethics, which brings together top specialists from around the world. We expect innovative papers and we have trust in the scientific rigor with which the topics will be addressed. The participants in both events will help to achieve a regional position for continued progress on the issue and to focus the national government's attention on this discipline. Science, technology and innovation – as essential elements to be considered in the development equation – will pave the way toward improving people's quality of life.

#### PERSPECTIVES FOR MEXICO. ELIAS MICHA ZAGA

We must remember that Mexico's National Development Plan 2013-2018 emphasizes the promotion of science, technology and innovation in order to leverage economic and social progress. It also highlights the commitment for a significant increase in investment and to design and apply differentiated public policies to push forward the states and regions lagging furthest behind.

As a brief conclusion, the Summit will be an excellent platform for Mexico to play a greater role in generating, acquiring and communicating knowledge of these issues, and also to make sure that bioethics is high on the public policy agenda.

Investments and new business opportunities are required for Mexico's economic development and to promote its competitiveness; bioethics can and must be factored into decisions because it regulates conduct that can have direct and indirect effects on people's quality of life. Both activities, the Summit and the Congress, apart from the ensuing dialog they will foster, represent a unique opportunity for scientists, academics and the general public in Mexico to find out more about bioethics through two of its most important sources.

CONACYT has helped bring these events to Mexico and we congratulate the Commission for making them a reality; we hope that the work is productive and helps to build the knowledge that we require in order to apply it for the benefit of society.





### PERSPECTIVES FOR MEXICO

#### Jose Ramon Cossio Diaz\*

On analyzing the agenda at the 12th World Bioethics Congress, one can see its relevance for lawyers and their enormous potential contributions toward bioethics. Therefore, it is most important that the law forms a part of meetings such as this.

One of the topics on the agenda is **global health**, with the subtopics of **prevention**, **promotion and culture in relation to health**. Among the Supreme Court of Justice's recent rulings, we can refer to the importance of the Law to Protect the Health of Non-Smokers in the Federal District, the subject of a ruling two years ago. There it was determined that the obligations established in this piece of legislation, in order to protect the health of smoker and non-smokers alike, were not in contravention of the right to private property, or the freedom of commerce, or the right to equality.

In terms of **distributive justice for health** – another item on the agenda at this Congress – enormous expectancies exist, since the new legal framework of the right to health protection is going to allow people greater recourse to the writ of amparo to request the recognition and defense of this right. Therefore, its component elements will be defined and situations will be determined, such as the type of medication to which one is rightfully entitled, for example.

In relation to **reproduction, start and end-of-life** issues, various decisions have been taken in regard to legislation in the states and in the Federal District. One of the most high-profile examples is the so-called "morning-after pill," in the state legislation of Oaxaca.

Also, in terms of **informed consent and agreement**, the Supreme Court must decide on the following questions: the elements that must be included in the letter of informed consent; when it must exist and when not; what is the responsibility of the physician, the hospital, and Mexico's health institutions, to name a few. This issue is particularly relevant when patients are those with some type of mental disorder. Recently there was a case of a young man with Asperger Syndrome, for which it will be necessary to determine if he should be under the care of his parents or if he is legally capable of taking his own decisions, based on his state of health. As part of this topic and

<sup>\*</sup> Minister of the Supreme Court of Justice.

#### PERSPECTIVES FOR MEXICO. JOSE RAMON COSSIO DIAZ

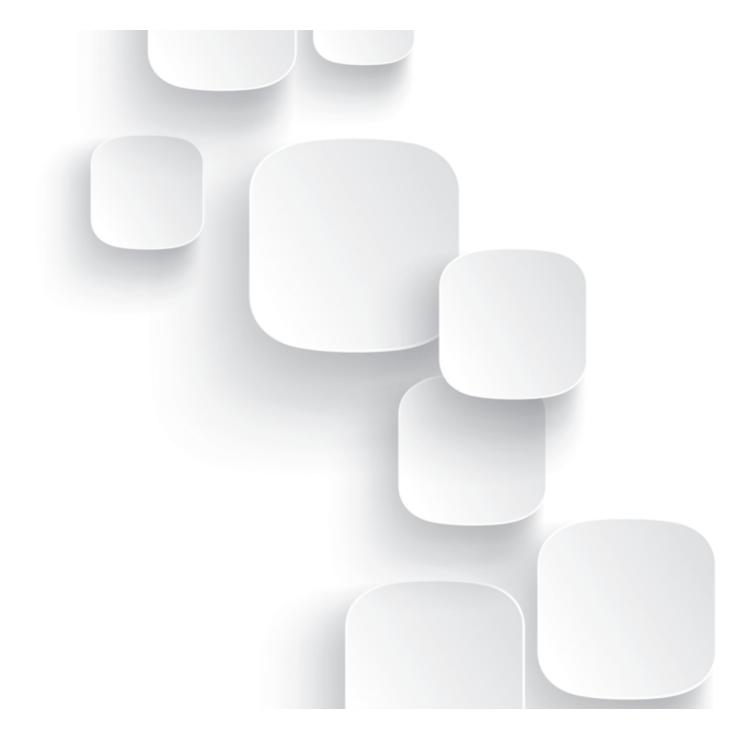
as an illustration, I can also refer to the highly important issues being addressed by courts, such as the autonomy of the individual, conscientious objection, and the responsibility of the various actors involved in the provision of health services.

Taking into account all of the above raises the question: why is it so important for lawyers to be involved in bioethics? I propose the following answer: because bioethics evolves more flexibly than the law, and the law can benefit from it. Lawyers operate according to the provisions of legal norms which, although created by a democratic society, cannot predict every hypothetical norm to be applied. People working on bioethics, meanwhile, can reflect on problems more freely, from scientific standpoints, without the normative limits within which lawyers must operate. Therefore, although we are faced with similar difficulties, bioethics offers a range of important solutions for different legal problems.

In turn, the relationship that I would like to show here also works from the point of view of the law; lawyers establish possible interpretations of legal norms and these must be taken into account by those working in bioethics, since the answer to a problem might be adequate from their perspective, but the legal consequences must not be disregarded. Those working in areas that have bioethical implications must understand the crimes and offences that exist, as well as the corresponding responsibilities and penalties, in addition to the general content of the norms which give meaning to the legal system as a whole.

Furthermore, it is important for lawyers to participate in meetings such as this which give us the opportunity to understand how boundary problems are being considered, through either real or hypothetical cases. I hope that many of my colleagues participate in this work.





# PERSPECTIVES FOR MEXICO

## Francisco Bolivar Zapata\*

It is a great honor for Mexico to have been chosen to host the 10th Global Summit of National Ethics/Bioethics Committees and the 12th World Congress of Bioethics, a decision by the WHO, UNESCO and the International Association of Bioethics to recognize the work and commitment of Mexico's National Bioethics Commission, as well as the talent and efforts of several of our Mexican colleagues, including: Juliana González, Dafna Feinholz, Guillermo Soberón, Adolfo Martínez Palomo, Ricardo Tapia, Ruy Pérez Tamayo, Rubén Lisker, Jorge Linares and José Ramón Cossío; members of the College of Bioethics, the Commission for Scientific Integrity and the Mexican Academy of Science; they have helped Mexican to become a leading country in this field and to ensure the success of these international events.

The theme of the Congress – Bioethics in a Global World: Science, Society and Individual – is a fascinating one. In a globalized world, science is one of the supporting pillars that guide the future of scientific knowledge in society, seeking the wellbeing of each and every individual within it. Therefore, it is increasingly urgent to insist on the issues

to be addressed at these meetings, namely: ethics in research; scientific integrity; conflicts of interest; data processing and privacy; DNA access; and new technologies, among others.

Health encompasses many of the most pressing needs of millions of people, which require deep ethical reflections: universal access to health services, hunger, malnutrition, epidemics, performance of health professionals and biosecurity. There are also social problems that constitute the greatest challenges for governments: poverty, ageing, migration, mental disorders, disability, and other dilemmas which force us to rethink relations between ethics, law, international cooperation, science, media, human rights, gender equality, etc.

Let us look at the role of science, scientific knowledge, scientific knowledge as an element that must support the decisions of governments and societies. In Mexico, the National Development Plan 2013-2018 and the Pact for Mexico clearly indicate that the mission of science, technology and innovation (STI) is that scientific knowledge and STI itself, should provide genuine leverage for social, economic and sustainable development. We insist that

<sup>\*</sup> Coordinator of Science, Technology and Innovation, Office of the President of the Republic.

#### PERSPECTIVES FOR MEXICO. FRANCISCO BOLIVAR ZAPATA

scientific knowledge must be based on decisions made by governments, but within the framework of bioethics.

We must highlight the fact that thirty per cent of the guidelines of the National Development Plan and over forty per cent of the commitments in the Pact for Mexico depend directly on science and technology. If we really want to make progress in the analysis and proposals of solutions to meet many of the needs of society and our planet, we must realize that it will not be possible to contend with them without STI. The health sector appears in the second objective of the National Development Plan, with five strategies and thirty-one action points to tackle Mexicans' health problems, and twenty-six of these points are supported by STI to make progress and address them.

I think it is important to emphasize that not all existing information has a scientific underpinning: much is false and irresponsible, if not immoral. We must be clear and write off magic, fantasy, charlatans and pseudoscience, which cannot substitute scientific knowledge and scientific experts.

Many offers of products available on the market lack any scientific, technological or ethical backing; "wonder" products allegedly have the capacity to cure and alleviate simultaneously many of society's ills, particular in regard to health. Therefore, we must praise the efforts by the Federal Commission for Protection against Health Risk (Cofepris) and the Secretariat of Health, who in this administration have worked more firmly to control and destroy these products, indicating the several of them can cause serious health damage.

Cofepris must be acknowledged for its work in unequivocally indicating the lack of any solid scientific evidence against transgenic food, which has been given the green light by the WHO, the FDA and other agencies. Lies and pseudoscience have been cited in an immoral attempt to demonize these products without any solid evidence.

This type of information, such as the supposed damage caused to health by genetically modified organisms, do not have any scientific basis. However, it is converted into a truth because the alleged harm is constantly repeated in the press, on the Internet, and other media, or by unqualified people with ulterior motives.

I would like to insist that in the global knowledge society, of which we are part, and about which Carl Sagan said "We have designed our civilization based on science and technology and at the same time arranged things so that almost no one understands anything at all about science and technology," we must progress toward using true experts in different areas, including bioethics, to support the decisions of governments and society.

It is extraordinarily important and strategic to protect and consolidate the efforts of nations to generate scientific knowledge, scientific know-how; preferably in relation to the various areas and sectors, health is certainly one of the most important. We must strive for this knowledge to help us understand ourselves and the universe around us in more detail, as well as our societies, as the basis for decisions.

I would take the Colegio Nacional's motto **Libertad por el saber** (Freedom through Knowledge) and add: **Mientras mayor el saber, mayor la libertad** (The greater the knowledge, the greater the freedom), hence we must have more closely guarded mechanisms, to prevent and punish fraud in the generation and publication of scientific knowledge.

I am certain that we must work harder so that science, technology and innovation – in the framework of bioethics – is more generally accepted by Mexican society as the basis for decision-making, and secure in the knowledge

that President Enrique Peña Nieto is committed to strengthening and consolidating the national system of science and technology.

I congratulate the organizers once again. The 10th Global Summit and the 12th World Congress will undoubtedly be extraordinary opportunities to reflect on and defend society's fundamental values, as well as to make progress on our understanding and analysis of bioethics.





## PERSPECTIVAS PARA MÉXICO

#### Jorge E. Linares Salgado\*

The National Autonomous University of Mexico (UNAM) has an outstanding tradition of research, teaching and cultural dissemination in the field of bioethics. For many years, numerous research groups, projects and academics have worked on bioethics with an interdisciplinary approach, scientific rigor and philosophical depth and, of course, from a secular and plural perspective, a fundamental characteristic of our university.

Therefore, last year the UNAM launched its **University Bioethics Program**, which seeks to organize and compile the work of undergraduates to push forward new research and collaborations, particularly with the National Bioethics Commission, with which we are working very closely. We wish to work in this way with other educational institutions in Mexico, as well as other bodies and institutions, such as the Supreme Court of Justice; in recent years we have sent this Court reasoned opinions on cases in dispute, when the Program was still a Research Seminar in Ethics and Bioethics.

We are convinced of the need for the UNAM - on account of its core functions and purpose, its research work and dissemination, as well as its social responsibility and undeniable international prestige - to participate now in order to offer its full support to the organization of these global bioethics forums in Mexico. It is an excellent opportunity for Mexico, and not only for the academic communities working on these issues but also to make the most of the activities of the World Congress as a motivation to spread a culture of bioethics in Mexico and to strengthen our national systems of health, education and scientific and technological development. The problems to be addressed at the world Congress and Summit on bioethics have a global dimension and must be discussed and resolved urgently; therefore we call on all participants to reflect, in a pluralistic manner, on the search for proposals and solutions, since these are essential for the fate of the world today.

The academics, who have been working for years in the field of bioethics within the UNAM, and also at other institutions in Mexico, will certainly make an impressive

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#### PERSPECTIVAS PARA MÉXICO. JORGE E. LINARES SALGADO

contribution to this World Congress. In particular, the presence of academics and specialists from Latin America, as well as those from Spain and Portugal, will also have a relevance not seen in previous years or at other congresses. We hope this will be the case as a result of Mexico being the host of these events, and because this can be used as a platform from which to re-launch and promote research, a plural and secular debate, as well as the dissemination and teaching of bioethics in every Ibero-American country.

The UNAM is proud to work alongside the National Bioethics Commission, offering our resources, full participation and experience in the organizing of these global meetings that correspond to Mexico as the global host of bioethics events in 2014. On behalf of my university and in the name of the UNAM's Rector, Dr. José Narro Robles, we offer our support and hope for both events to be resounding successes. We are confident that the Congress and the Global Summit of Bioethics will lead to outcomes that will benefit human communities and living beings all around the planet.





# **MEXICO'S COMMITMENT**

## Mercedes Juan Lopez\*

It is an honor for Mexico to have been chosen as the venue and organizer of the 10th Global Summit of National Ethics/Bioethics Committees and the 12th World Bioethics Congress. Today's events are announced during this new government administration and will doubtlessly influence the new approach and design of new public health policies.

Mexico's president has told us to work on consolidating a government based on a society that respects rights, for a Mexico that is peaceful and inclusive, with high-quality education, a wealthy Mexico with a global outlook, moving decisively toward fulfilling its potential. A society in which the right to health protection, enshrined in Article 4 of Mexico's Constitution, is translated into facts in favor of health, the quality of life and human development.

One of the main objectives of the 2013-2018 National Development Plan is to ensure effective access to quality health services. Mexico is moving toward the construction of a national public health system so that every Mexican

citizen can effectively receive standardized healthcare at any institution of public health, with a gender focus and an emphasis on primary healthcare, prevention and promotion of health at every stage of the process.

For all these reasons, we must strengthen and push forward bioethical principles and ensure that all actors involved at the different levels of healthcare take an ethical and social approach to their work.

Although much remains to be done in regard to bioethics in Mexico, we cannot ignore the major achievements to date, such as the establishment of the lead entity for this issue, the National Bioethics Commission.

In a similar vein, the reforms to the General Health Law, made two years ago, refer to the requirement of public and private health institutions to establish hospital bioethics committees and ethics committees in the field of research. In this area, we must also make special mention of the active participation and co-responsibility of public and private educational institutions that carry out research on human beings and which are also subject to this requirement for an ethical approach.

<sup>\*</sup> Ministry of Health, México.

#### MEXICO'S COMMITMENT. MERCEDES JUAN LOPEZ

These initiatives will certainly provide greater ethical certainty in healthcare work, as well as a plural approach to the ethical dilemmas that arise – both in hospitals and in the development of biomedical research from an inclusive, plural, multidisciplinary and non-discriminatory perspective.

The international scope of this afternoon's events undoubtedly form the framework needed to promote and disseminate – in Mexico and around the world – the culture of bioethics which are of crucial importance during this time of building a globalized society, a knowledge society with fast and powerful media, and also a society which is struggling to maintain its identity with extreme economic, social and cultural polarizations.

The 10th Global Summit of National Bioethics Committees and the 12th World Bioethics Congress will provide a showcase for successful experiences that have raised the importance of bioethics on the health agendas of our respective countries.

Today we are launching two international events, to be held June 2014, that are fundamentally important for the work of national ethics and bioethics committees around the world, and that will address specific topics, mentioned earlier, that are of enormous consequence.

Our society needs bioethics as a tool to help safeguard human rights and dignity in the application of the specific knowledge contained in the life sciences.







# **WELCOME AND OPENING**

#### NATIONAL INSTITUTE OF GENOMIC MEDICINE

Dr. Xavier Soberon Mainero\*

Our work at the National Institute of Genomic Medicine (INMEGEN) is strongly related to bioethics, because we understand that this is a field that goes far beyond medical ethics, and our research into topics within our field represents changes in how we perceive ourselves and, of course, how we are going to handle our relations, processes and procedures.

Bioethics, understood as what impacts on humans in regards to the management of living things, becomes necessary in many aspects of contemporary biotechnology. In this regard, INMEGEN shares this interest and close links to bioethical issues, because much of our work here involves the use of latest technologies—DNA sequencing, nucleic acids, managing clones, and different organisms modified and processed in the laboratory. We also use these technologies for research on human beings, which requires informed consent and other relevant issues.

Not a week goes by without some new discovery or progress being announced that is a cause of concern to us and that calls for a thorough analysis of the possible implications of its use, and also of the precautions that may be necessary in order to prevent this knowledge or these new technologies being misused.

We must be very active in analyzing these issues and handling them professionally, based on scientific evidence and from a secular standpoint – a requirement for a country such as ours.

I would therefore like to congratulate the National Bioethics Commission for being chosen as the host of the international events to be held in 2014. And Dr. Manuel Ruiz de Chávez must also be congratulated for all his hard work and enthusiasm in placing Mexico on the global stage of bioethics.

<sup>\*</sup> General Director of the National Institute of Genomic Medicine (INMEGEN).



# THE NATIONAL COUNCIL OF SCIENCE AND TECHNOLOGY AND THE ETHICAL DEVELOPMENT OF SCIENCE

## Dra. Julia Tagüeña Parga\*

The central theme of the 12th World Bioethics Congress – global health, science, society and the individual – is fundamental for the National Council of Science and Technology (CONACYT). In science, one must defend ethics in conducting research with integrity, for example in processing data. Society faces a long list of ethical dilemmas, and protecting equality and interculturality must be of paramount importance. For individuals, there is a responsibility in regards health and society.

CONACYT wants to apply an ethical code throughout its work, to act transparently and to foster gender equality, care for the environment, and sustainable development in all of its projects. In terms of health, ethics improves the quality of care and respect for users, whereas bioethics has a much broader impact, since it dignifies and protects human rights and eliminates discrimination.

We live in a complex world, and we receive constant reports of unethical acts. Our society is undoubtedly facing a crisis of values, plagued by extremism and violence across the planet, our only home. For all of these reasons, the existence of ethics and bioethics commissions gives us hope for the future of humanity.

In his book Ética para Amador, Fernando Savater writes: "Unlike other living or inanimate beings, to some extent we as humans can invent and choose our way of life, we can opt for what we consider good or suitable, as opposed to what we perceive as bad or unsuitable. And just as we can invent and choose, we can also make mistakes. Therefore it seems sensible to pay attention to what we do, and to seek out a certain wisdom to help us make the right decisions." (F. Savater: Ética para Amador. Barcelona: Ariel, 1992).

This wisdom or art of living is what is known as *ethics*. Clearly there are some things which are suitable for our lives, and others that are not. We cannot define what is going to happen to us, but we can choose how to deal with what happens to us. In other words, ethics is a consequence of freedom, of being able to make a decision.

<sup>\*</sup> Associate Director of Scientific Development National Council for Science and Technology (CONACYT).

#### WELCOME AND OPENING. DRA. JULIA TAGÜEÑA PARGA

I would like to end with some words by Octavio Paz, taken from his book *La otra voz*, on freedom: "Freedom is not a philosophy, nor is it even an idea, it is a stirring of consciousness that leads us, at certain moments, to utter one of two monosyllables: Yes or No. And in their fleeting brevity, like a flash of lightning, the contradictory character of human nature is revealed." So, let us say Yes to defend bioethics and human rights. (O. Paz, *La otra voz.* Poesía y fin de siglo. Barcelona: Seix Barral, 1990.)







## NATIONAL COMMISSION OF BIOETHICS

#### Dr. Manuel H. Ruiz de Chavez\*

I would like to express my thanks to all those present for their participation, and of course to all our speakers, who will be addressing a wide range of vital questions from the current perspective of bioethics in Mexico and the world, and to Xavier Soberón, our host at the National Institute of Genomic Medicine.

I would also take this opportunity to highlight the work of pioneers in this field, active promoters of bioethics in Mexico. I refer to Dr. Juliana González, who is with us here today, Dr. Adolfo Martínez Palomo, Ricardo Tapia, President of the College of Bioethics, and members of the Council at the National Bioethics Commission, such as Jorge Gaxiola, Emma Verástegui, and also Jorge Linares, Coordinator of the University Bioethics Program, with whom we have been working on joint projects.

I am also grateful for the presence of Dr. Julia Tagüeña Parga, Scientific Director at the National Council of Science and Technology, who has tirelessly promoted our initiatives. Thank you for supporting our first steps toward bringing these events to Mexico; this support gives recognition to generations of work carried out at several Mexican institutions.

This opening International Symposium forms part of the launch of the 10th Global Summit of National Bioethics Committees and the 12th World Bioethics Congress, events supported by the World Health Organization as the Permanent Secretariat and, of course, with the participation of other international organizations such as UNESCO, through its Department of Bioethics, led by Dr. Dafna Feinholz; the International Association of Bioethics, represented here by its president, Dr. Angus Dawson and Professor Inez de Beaufort, who chaired the World Bioethics Congress held in Rotterdam in 2010.

Both of these events are of the highest importance in the field of bioethics, and they have been held uninterruptedly since the 1990s. These biennial congresses have produced significant results, both in terms of enhancing the performance and consolidating the work of national

<sup>\*</sup> Council President, National Bioethics Commission.

#### WELCOME AND OPENING. DR. MANUEL H. RUIZ DE CHAVEZ

bioethics commissions, and in the processing, consideration, analysis and exchange of information on bioethics and its end purposes: safeguarding people's health, life in all of its forms, and the habitat itself.

In addition to the introductory remarks, the following pages contain nine papers by nine leading experts in this field. These discuss various issues of utmost importance, ranging from bioethics in defining health priorities, strengthening the legal framework of this extensive area of knowledge, to bioethics in educational institutions. We even include topics that take a wide perspective, such as bioethics in the global sphere, among other fundamental issues.

The Summit is a meeting promoted by the Assembly of National Ethics/Bioethics Committees from World Health Organization member countries; it is organized jointly with the WHO's Permanent Secretariat and, on this occasion, also by Mexico's National Bioethics Commission.

The Summit convenes over one hundred countries from all across the world, as well as numerous representatives from other international organizations. The first Summit was held in the United States in 1992 and since then it

has taken place biennially nine times in various countries. In 2014, Mexico will be hosting the event for the first time; the only previous Latin American edition was held in Brazil more than ten years' ago.

The World Bioethics Congress, for its part, is one of the highest-level academic meetings for disseminating news about findings and new theoretical perspectives on ethical questions resulting from progress and potential consequences of science and technology on life – not only human life but also in regards to the safeguarding of the environment as a whole. This event is organized by the International Association of Bioethics, a global organization with a network of experts from around the world.

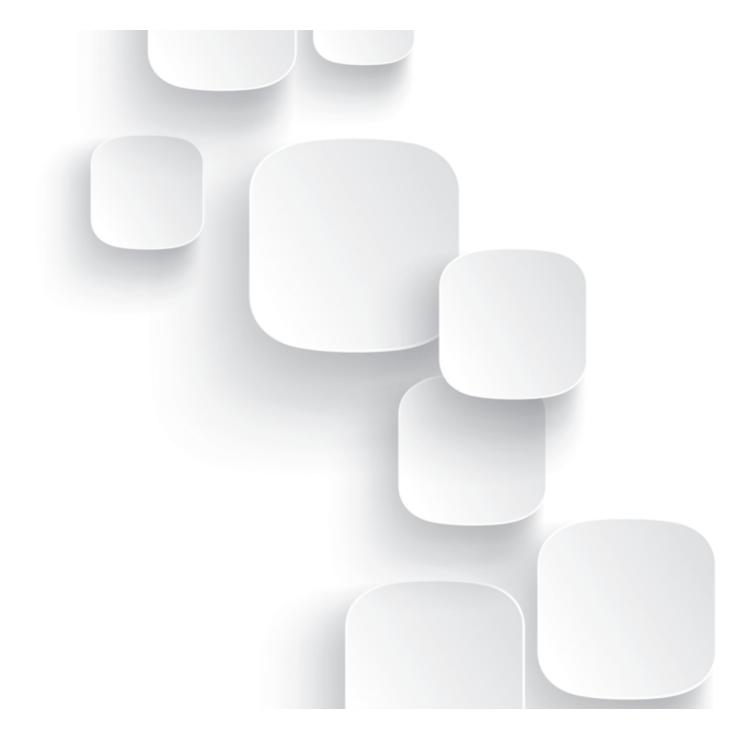
We must highlight the work of the participants in this Symposium who have been pioneering and active promoters of bioethics in Mexico. For example, Dr. Juliana González, Dr. Adolfo Martínez Palomo, Dr. Ricardo Tapia – President of the College of Bioethics – and the Council members of Mexico's National Bioethics Commission, such as the distinguished lawyer, Jorge Gaxiola.

#### WELCOME AND OPENING. DR. MANUEL H. RUIZ DE CHAVEZ

I think it is also important to mention Dr. Julia Tagüeña Parga, Scientific Director of Mexico's National Council of Science and Technology, who has tirelessly promoted our initiatives. Thank you for supporting our first steps toward bringing these events to Mexico, which recognize the work carried out by several Mexican institutions.

This collection of texts is a compilation of contributions made by leading national and international specialists: Maureen Birmingham, Angus Dawson, Inez de Beaufort, Jorge Gaxiola Moraila, Juliana González, David Koepsell, Jorge Linares Salgado, Adolfo Martínez Palomo, Gabriel O'Shea Cuevas, Guillermo Ruiz Palacios, Xavier Soberon Mainero, Julia Tagüeña Parga, and Ricardo Tapia Ibargüengoytia. I would like to express our appreciation to them all.





# **BIOETHICS, PUBLIC POLICY AND EDUCATION**

#### **BIOETHICS IN DETERMINING HEALTH PRIORITIES**

Cesar Humberto Botello Ortiz\*

Bioethics, Potter states, is a new scientific ethic that combines humility, responsibility and skill; it is interdisciplinary and intercultural; and it intensifies the meaning of humanity. Justice is one of its principles and it examines the social repercussions of biomedical decisions to ensure a fair distribution of costs and benefits for everyone.

The explicit definition of priorities in health interventions comes as an opportunity for Mexico to balance the pressure and complexity of an advanced epidemiological transition, with policies based on evidence generated by the quest to find how to optimize the use of scarce resources to improve the population's health. The Mexican experience in defining priorities shows how standardized analytical approaches in decision-making, for example with regard to cost-effectiveness, combine with other criteria to respond to patients' legitimate expectations and to ensure fair financing for families.

For public policy, the implications include choices on the use of available and proven analytic tools to define national health priorities.

In Mexico's Constitution of 1917, the original idea of protecting people's health was conceived in relation to social security benefits for the working class rather than as a right for all Mexicans. Health was declared a fundamental human right at the International Conference on Primary Health Care held in Almaty (formerly Alma-Ata) on Septemberb 12, 1978. This declaration expressed the need for urgent action by all governments, health and development workers in the global community to protect and improve the health of all people. Subsequently, on February 3, 1983, an addition was made to Article 4 of the Constitution to give every person the right to health.

An executive order was issued on May 15, 2003, to amend and add a public health insurance system (Sistema de Protección Social en Salud) to the General Health Law, specifying that "all Mexicans without formal access to health services have the right to be covered by his

<sup>\*</sup> Senior Advisor of Dr. Gabriel O'Shea Cuevas (National Commissioner of Social Protection in Health, Seguro Popular).

system. Through this mechanism, the Mexican State will guarantee effective, opportune, high-quality access, at no cost at the point of provision and without discrimination, to surgical, pharmaceutical and hospital services that meet citizens' every healthcare need."

This is provided through the combination of measures to promote health, prevention, diagnosis, treatment and rehabilitation, prioritized according to criteria of safety, effectiveness, cost, effectively, adherence to professional ethical standards and social acceptability.

The bioethics of public health is understood as the moral result of a set of decisions and health policies which boost public participation and social distribution and involve a process of analyzing the ethical aspects of matters inherently related to the implementation of public health services. This encompasses the personal and collective spheres, giving rise to the concept of solidarity, in which every member of a community cooperates according to their means, in order to meet the basic needs of the entire population, and equitable services are provided with the aim of improving people's quality of life and respecting human rights without jeopardizing individual interests.

Since Potter decided to create the multidisciplinary movement of scientists to research questions involving ethics and biomedical sciences, a roadmap has been drawn that leads toward an increasingly wide-ranging study, within an international context that comprises traditional aspects of medical ethics, environmental ethics, debates on the rights of future generations and sustainable development, as an instance of practical judgment implemented under specific circumstances. This development has a practical aim, to be achieved through the institutionalization of knowledge about morality, new ways of living, dying, being born, curing and caring.

The challenge lies in guaranteeing fair and equitable access to services, and for these services to be provided with quality and warmth, according the principles of bioethics and legal provisions in force.

No place on Earth can have enough resources to meet every socio-medical need. Priorities must therefore be established, in order to assign more resources to create a greater social impact. Fortunately this has resulted in several actions to bring about fair health care as an inalienable right. Similarly, distributive justice and welfare studies have been developed, and these are reflected in actions to protect and defend human rights, and in the need to prioritize care for the economically and socially marginalized population: new vaccination schemes are being introduced, as well as measures to prevent eating disorders, to improve care for the elderly, and to prevent and treat chronic degenerative diseases such as diabetes, among many others.

According to Diego Gracia, we must bear in mind that bioethical healthcare treatment is not the same as hospital healthcare and therefore the two must be approached differently. "The ethical conflicts that must be solved, or the methodology needed by a doctor working in an intensive care unit in order to solve them, will be completely different to the methodology needed to educate a population as a whole about healthy, hygienic and sensible lifestyles."

We must therefore consider healthcare budgets, and the serious ethical dilemmas related to their distribution and the criteria that must be applied when assigning them, so that they are efficient and enable fair and equitable healthcare; this requires a transparent analysis of how this budget must be implemented, since its improper use is detrimental to the principle of welfare and violates the principle of distributive justice.

Bioethics in health requires us to evaluate the criteria of prioritization with an efficient theoretical underpinning that establishes a proper control of resources, since unjustified increases to budgets do not always represent improvements to healthcare. In this sense, both decision makers and healthcare professionals must act as managers of health resources in order to provide a decent and cost-aware medical service.

Healthcare managers have the moral obligation to manage health resources efficiently. It is the proper use of new medical technology which has generated a series of dilemmas that must be taken into account. Firstly, we must identify the potential benefits provided by curing diseases that used to be incurable, and how this can enable us to prolong people's lives, which then entails new health needs and resources. Secondly, we must evaluate the quality of life and the meeting of each individual's expectations on the basis of moral, ethical and sometimes legal implications.

Bioethics must therefore increase people's recognition of factors that influence society's health, as well as continue generating an awareness of values and ethical principles to establish health priorities effectively.







#### STRENGTHENING THE LEGAL FRAMEWORK FOR BIOETHICS IN MEXICO

#### Jorge Gaxiola Moraila\*

Let me begin with a series of questions: What happened after the 1983 constitutional amendment which guarantees the right to health as a fundamental right (previously defined by the Constitution as an "individual guarantee")? An amendment to the Constitution, an international agreement, an acknowledgement, an emphatic proclamation of rights. But what really happened? What happened to people's health, social security, access to services and medicines?

Because the law has been understood, especially in regard to fundamental rights, as a basic question, as a more emphatic question, sometimes poetical or lyrical. That is the position at international forums, a rather cosmetic issue of how it is presented, rather than a commitment to change or effective guarantee. In that context, any discussion about modifying or modernizing legal issues related to bioethics might seem utterly irrelevant. But this is not true: it has gained importance because things have changed.

In 1983, when the Constitution was amended to incorporate the right to health as an individual guarantee, these rights have largely had an impact that has been more emphatic than normative. In other words, in practice, the rights were not effectively linked to the conduct of people who were considered more liable to respect rights, or who had greater authorization to exercise their own rights; it did not seem to change either the government's public policies or judges' deliberations.

Subsequently, particularly since the 1980s and perhaps from the 1990s, a powerful international movement has sprung up. It can be summed up as "fundamental rights are not announcements, they are rules of conduct," and therefore they are binding for authorities, give rights to individuals, and require judges to implement them.

This has taken place around the world, and has significantly altered how justice is dispensed in the courtrooms and how laws are worded in legislative instruments. In particular, it has led to changes in people's lives, in terms of their access to health services, respect for their dignity, freedom in the provision of the services, and the rigor of medical research.

<sup>\*</sup> Lawyer from the Escuela Libre de Derecho; appointed by the President as Official Advisor of the taxpayers' legal defense office (Procuraduría de Defensa del Contribuyente).

In Mexico, progress has been gradual, as is often the case with such things. But in 2011, something happened that accelerated the change and made a difference. A constitutional reform was made – again it appeared cosmetic and was presented to the media as if it were simply a linguistic matter. "Individual guarantees" were replaced with "fundamental rights," and "individual guarantees offered by the Constitution" with "human rights recognized by the Constitution." This turned it into a topic for philosophers, political theorists, publicists, and I might dare to add, gossips.

Immediately after this reform was published, the Supreme Court of Justice established that human rights must be implemented as supreme norms, in other words, regardless of whether they are inscribed in an international treaty or in the Constitution, hence they have a practical impact. They are not statements, they are rules, and judges and public officials are required to make them count and to protect them; individuals have the same obligation vis à vis other individuals; the protection of this right enshrined in this norm can be legally enforced.

Consider the practical importance: judges can cease to apply ordinary laws, regulations, guidelines, or any type

of provision that obstructs compliance with a human right expressed in the Constitution or an international treaty. Let us consider some recent rulings, not only by the Supreme Court but by all the courts: local, of the first instance (trial level), federal, of the second instance (appeals level), administrative, labor, etc.

Instead of limiting themselves to interpreting the law, now they consider why they must understand how the law works in the framework of human rights and how to make that law a means of acknowledging and specifying and progressively promoting these human rights; they must check whether there is a conflict between the human right enshrined in a treaty or the human right, for example of health, independence, free choice in the context of bioethical dilemmas; if there is a dilemma between these laws and the Constitution, or a dilemma between these laws and international treaty, they must nullify the law issued by the Congress of the Union and make it inapplicable.

This might continue to seem like a lecture, but we must look at rulings and see how judges are saying: "this person has the right to such-and-such according to the law, but it affects the human right of another person, therefore the right of the former does not exist, but the law passed

by Congress is inapplicable because it is affecting a fundamental right." This is a major change. We have seen it in high-profile cases reported in the media, for example in the release of Florence Cassez and Caro Quintero, and the obligation to pay the medical bills abroad for someone who filed a lawsuit, exercising their right to health on the basis of San José de Costa Rica's Charter of Human Rights. We can also refer to the ruling made by a judge who ordered the State to pay a woman's maintenance, because the husband could no longer do so and this exposed her to a level of life that is lower than that required to live in dignity. The implied budgetary impact makes it a dangerous and difficult change, but an important one.

I think bioethics is currently at a vital juncture but it must use the law and public institutions to be genuinely and effectively put into practice. All these legal changes around the world, and particularly during these times in Mexico, can be used to convert bioethical imperatives into realities as part of medical practice and research, as well as in every other field of research.

I have the catalog of constitutional, health-related reforms: public health, workers' health, children's health, prisoners'

health, etc. I won't mention them all, but I want to tell you that the Constitution has been gradually modified to create special regimes suited to different social sectors in relation to health.

A recent reform, in July 2013, additional to another one passed in November 2012, which is central to the issue of bioethics, refers to the Constitution establishing secularity as a fundamental issue; it establishes the secular State. This must be obligatory in the decisions taken by the government and individuals whenever a fundamental right or freedom is at stake.

What is secularity? It refers to a critical, objective, rational, considered approach, open to problems, acknowledging plurality. It is tolerance, not as an act of supporting but respecting differences and in that sense it solves ethical problems that often become complicated by the intervention of religious or dogmatic arguments that the Constitution now clearly prohibits.

In reference to legislative issues, I would like to single out a couple of changes. The National Bioethics Commission is a decentralized government agency. In other words, it is a part of the Secretariat of Health, and was created by an executive order. It acts on a strictly consultative, advisory, analytical and interlocutory basis, an extremely important role, and it has therefore carried out crucial work in medical practice and research. However, following the reforms to the General Health Law in December 2011, for the first time the National Bioethics Commission has been recognized, no longer in an executive order, but in a law passed by the Congress of the Union; and it is no longer simply a consultative and advisory body but a principal body that regulates how bioethics committees form and operate in the field of medical practice and investigation.

It represents an enormous challenge to establish guidelines for committees' work, to ensure those responsible are effective, efficient, analytical, secular, tolerant, rational, ethical in their research and medical work in situ, since in reality we are further removed from ethical dilemmas than doctors and researchers are, with the particular complexities of each case and existing resources.

This challenge has been adopted following an executive order, and has been unanimously assumed by the Council under a fundamental principle of listening. These guidelines were already published and the National Commission

has the commitment to listening to the state committees, hospitals' bioethics committees and the ethical committees in research: how they operate, how they can be formed, who can attend and who cannot, what responsibilities they can take on, what type of dilemmas they face, how they resolve them. And using that information, which can only come from these committees and local commissions, we can work toward improving this set of rules, so that the mission is effectively carried out in hospitals and research centers; not on desks. We need and seek more dialogue with local courts.

We must also revise the Commission's institutional framework, since it has been growing. The law gives it powers it previously lacked, even rule-making faculties; to put this in legal terms, it is now an authority yet the rules applying to it still date from its previous organizational set-up. We must revise the institutional structure, its legal character, its organizational shape: the organization contemplated in the executive order has not been entirely compatible with the rules, systems and budgets handled by Mexico's globalizing entities. With that purpose in mind, the Commission is carrying out important work that will lead to a review of its order.

I believe that the events in 2014 will offer a great opportunity to renew and consolidate the National Bioethics Commission's leadership. In conjunction with the state commissions, and working in contact with the committees, it can make Mexican society less discriminatory, less unequal, fairer and better able to meet its healthcare responsibilities.

Finally, now that the treaties have practically become a Constitution for Mexico and are directly applicable in the courts and by authorities, I would like to call for a reflection on the international legal framework for bioethics. Many international declarations and consensuses exist on bioethics, but very few are binding, obligatory, or are international treaties ratified by the States that are signatories, extra legal norms and not only bioethical principles of consensuses or of associations.

By time of the Global Summit and World Congress, I am confident that – with this new legal system in place, and with a proposal for international regulation – we will be organically stronger and more effective.





## **BIOETHICS IN EDUCATIONAL INSTITUTIONS**

## Jorge E. Linares Salgado\*

Numerous bioethics study programs now exist around the world, particularly at a postgraduate level. These courses are either provided online, on-site or as distance education. Bioethics is also addressed in several other ways – in magazines, conferences, forums, radio and television programs, museum exhibitions – demonstrating the importance and cultural expansion of the subject around the world, and especially in countries such as Mexico.

Educational institutes in Mexico provide various formal courses on bioethics. The National Autonomous University of Mexico (UNAM) opened its postgraduate program on bioethics 15 years ago, thanks to the initiative of Dr. Juliana González, emeritus professor of the university's Faculty of Philosophy and Literature. Currently the bioethics masters and doctoral programs offered at the UNAM form part of the medicine and health sciences postgraduate courses.

Over this period, those of us who have been working toward consolidating academic education in bioethics in Mexico have faced – in my opinion – two main problems. On the one hand, interdisciplinarity: in other words, the

combination of various disciplines involved and combined in the field of bioethics. This interdisciplinary combination represents a core methodological problem, one we yet to solve and that is an obstacle facing academic programs the world over, especially in terms of its design and operation. Because bioethics is not a traditional discipline, in the sense of other disciplines such as biology, physics or philosophy, it lacks a canonical body of concepts and theories, as Engelhardt would say. Bioethics does, however, combine traditions of thought, traditions that mainly originate from ethical questions, and a series of problems that have now been standardized, and that are the subject of extensive analysis from a wide range of moral, political – and sometimes divergent – perspectives.

This interdisciplinary quality has become a point of arrival rather than a point of departure, complicating the definition of the bioethics study program graduate profile. This aspect has made it extremely hard to draw up an undergraduate study program for bioethics. We have therefore found that prior studies in another discipline are required, along with a certain level of professional experience (in medicine, law, health sciences, philosophy, psychology, sociology, anthropology, etc.), even in the

<sup>\*</sup> Full-time faculty member of the UNAM's Faculty of Philosophy and Literature.

field of research, in order to be able to tackle some of the wide-ranging and critical issues of bioethics from an academic perspective.

Nowadays we cannot reduce bioethics to medical problems and biomedical research, not even to problems that purely affect human beings. We must develop a more fundamental and primary concept of bioethics, such that proposed by Potter: a broad approach to environmental problems, problems in the relationship between human beings and other living beings, and a critical and profound reflection on environmental deterioration and humankind's responsibilities for protecting biodiversity.

The range of interdisciplinary problems in bioethics is one of the challenges that must overcome by all educational institutions which propose to create formal study programs in this field, with a particular focus on defining the graduate and the professional who is going to work in society or who will help solve problems related to bioethics.

The other great problem is the plurality of moral opinions, theoretical perspectives and what I would even refer to as "scientific cultures" that converge in bioethics: experimental and theoretical sciences such as philosophy.

This is a fascinating problem to research but a very difficult one to solve, because a very disparate range of languages and traditions are created or come together in bioethics studies, and these can often end up confusing the students themselves when it comes to choosing or combining perspectives which turn out to be incompatible. The main problem here lies in the fact that bioethics has become an unprecedented interaction between science and the humanities, as well as a plural and intercultural public dialog.

Morality or axiological perspectives also come into play with the plurality of bioethics. Different moral traditions converge and diverge within it, and sometimes religious perspectives are at odds with secular perspectives. Therefore, the interdisciplinarity and moral plurality are the most marked traits of bioethics in societies – such as Mexico's – that are heterogeneous and have democratic and tolerant aspirations.

In order to reach legitimate agreements that regulate techno-scientific interventions, as well as to ensure the protection of living beings in general, and not only to consider human lives, it is essential that plurality is reflected in debates, research and proposals, for an analysis of the bases and consequences of each one of the actions and principles that are established. Because debates on bioethics do not involve only a school of thought, but also the personal moral convictions of those participating in the debate. This aspect can also be seen in the various scientific disciplines; these internal debates must also be considered in bioethics as problems of interacting and shaping traditions of research and the confronting social interests of scientists which go beyond the merely epistemological or scientific, and relate to economic and socio-political interests.

Philosophy has traditionally been a plural and divergent discipline, since no ultimate and unanimous agreement can be reached between its wide variety of schools – such as Pragmatism, Utilitarianism, Contractualism, Personalism, Kantism etc. – which predominate in contemporary bioethics.

As pointed out by a Belgian colleague and teacher, Professor Gilbert Hottois, every professional who participates in a debate on bioethics, in the education of professionals in bioethics or in bioethics committees, represents a specific position, has particular interests, an educational background and an affiliation with a specific moral tradition.

It is therefore common to find more disagreements than agreements in these discussions. Nevertheless, certain consensuses and agreements of principle can be reached, since bioethics seeks a practical (and sometimes urgent) end, and thus cannot remain solely as a theoretical and speculative confrontation.

Also, each individual, all scientists, philosophers, lawyers, have their own moral concepts – some of which are religious – their own biases and their own cognitive limitations. This is a matter that must be clearly debated in the academic education in bioethics. In other words, students or specialists in bioethics must be capable of self-criticism and self-reflection to question their own prejudices and entrenched ideas; and they must be tolerant in order to listen and be open to other ideas about human life, death, health, nature and life in general.

Philosophical and even scientific discrepancies, which are inherent in bioethics and which cause sometimes very fierce controversies, have contributed to the acknowledgement of the range of interpretations of many moral concepts that seemed to have a unanimous meaning, at least in Western societies.

### BIOETHICS, PUBLIC POLICY AND EDUCATION, JORGE E, LINARES SALGADO

This has been the case with notions such as person, personal identity, dignity, intrinsic value, moral agency, moral relevancy and status, but also dynamic concepts such as distributive justice, responsibility and precaution, to give just a few examples.

Each one of these concepts, which occasionally tend to be brandished as if they were pre-fabricated formula, implies a discussion and a reformulation of their perspectives. Academic education in bioethics must therefore be provided in educational institutions that must help shed light on this analysis, argue more rigorously not only in terms of a conceptual analysis but fundamentally in regard to the consequences of acts and to their underlying principles.

Bioethical methodologies can therefore be very diverse. No unique methodology exists in the field of bioethics. As I said at the beginning, there is no uniformity and, as of now, that is a positive thing, because it leads to an open debate in which anyone can participate and it even stimulates creativity. But on the other hand, it seems to be a weakness in the discipline.

With a view to reaching some consensuses on ethical principles which must be the shared starting point for action and the means of regulating ethics and many of our techno-scientific practices on an ethical and legal basis, in our human relations and in the relations between humans and other living beings, it will be necessary to put to the test (this should be the purpose of the academic education) the theories, values and all the moral conditions which converge in debates on bioethics.

Secularity, in my opinion, is an essential aspect both in academic education in bioethics and in committee and public debates on the subject.

Around the world, religious bioethics is very active and well organized, principally by the Catholic Church. However, our fundamental conviction is that academic education must be primarily secular and not religious. It must be based on solid arguments, using scientific evidence and well-founded philosophical theories. A broad and stable social consensus is only achievable in this way, through a discussion that is sufficient in order to reach common agreements that make it possible to regulate and effectively improve our practices, reduce risks and harm, and provide fairer guarantees for the social benefits offered by sciences

and techno-sciences of life. Therefore, a secular approach – an essential aspect of education in bioethics in academic institutions – is added to the subject's interdisciplinary plurality.

However, this does not imply that moral concepts, knowledge, cultural traditions and every type of concept, including religious ones, should be excluded from debates on bioethics. Bioethics is nourished both from scientific knowledge and from the moral understandings of social traditions and cultures.

In every society, and particularly in multicultural countries such as Mexico, sharply contrasting moral concepts and practices coexist, and no single one must be arbitrarily imposed on the others, neither on account of its longest tradition, nor for being predominant or supported by a majority. The only principles and norms to count must be those which can legitimately achieve a consensus between cultural and moral diversity, and which have solid reasons that demonstrate benefits when converted into practical norms.

This legitimacy will depend on their universality and their rational underpinnings, but above all – as I specified above – on their probable or verifiable practical consequences.

Many discussions have focused on the possibility of reaching a universal set of ethical principles or a basis of generic principles that can be shared across cultures. This is an ongoing debate, and no conclusion will be reached in the immediate future. But bioethics can contribute to this discussion, from the dual perspective of practice and theory. However, this must be based on a public debate, on a practical reasoning put into collective action, on a willingness to reach agreements, on an offer of reasons, on submitting our principles to scrutiny and an analysis of rationale, and on arguing the case. Only in this way is it possible to reach agreements and find legitimate consensus for everyone's benefit.

In other words, one of the ultimate objectives of academic education in bioethics is fundamentally practical; we are interested in producing researchers but also people who might participate in debates by using arguments, who have the capacity to reason, to be tolerant and willing to reach agreements. This dual aspect is currently established in many bioethics studies, therefore a practical education is given precedence over a purely theoretical approach.

At the UNAM we have maintained this dual principle; we have been trying to educate high-level researchers so

they might work in an interdisciplinary context in any of the areas of bioethics, without losing sight of the practical qualifications of someone receiving an education in this field.

Further to the above, the figure or profile of the bioethicist is also under discussion. I consider that this term is not particularly helpful since bioethics is not a discipline but a set of disciplines, of different topics, and it implies a continuous dialog. Therefore we cannot think of someone or a group of people who solve bioethical problems on a professional basis, but instead we must always think about the interdisciplinary and plural dialog of different people, with different educations, and with different traditions, who can reach agreements.

In any case, bioethicists would have a little more training in order to be able to lead some of the debates, but they would never be able to become the expert that might replace deliberation and debate – something that anyone can access through the use of their own capacities.

I therefore believe that in the need to consolidate the characteristics, briefly mentioned above, in regard to academic education in bioethics. We must bear in mind that bioethics has developed very quickly – it is a relatively recent discipline in global academic history. Also, as I remarked earlier, there is a wide range of studies, ways and means of carrying out academic education. In that sense, we must have a process of consolidation in bioethics, as an interdisciplinary, innovative and complex means of solving very urgent, practical and immediate problems, which are not only identified with the difficulties that arise in a hospital or a research center, but which involve the natural environment, social and global order that affects us all in equal measure, humans and other living beings.

In my opinion, by consolidating studies in bioethics in various parts of the world, it will become possible to contribute to the education of societies that are much more tolerant, rational and capable of adapting to important changes in the contemporary world; societies which recognize and tackle moral plurality, which attempt to solve serious human problems such as increasing inequality, and most of all, which think and act not anthropocentrically but much more broadly, more empathetically, more linked to our terrestrial reality, in order to rebalance the relationships between human beings with the rest of the living beings with whom we share our existence on this planet.





# **BIOETHICS WORLDWIDE**

### **BIOETHICS AND PUBLIC HEALTH**

Dr. Angus Dawson\*

Thank you very much to the organizers for inviting me to give this talk today. I apologize for the fact that I have to speak in English.

Over the last few years, I've been involved in a project trying to refocus bioethics upon thinking about issues from the perspective of public health. The title of my talk is 'Public Health and Bioethics', and what I would like to do is provide you with some idea of how it is possible to think of bioethics from the perspective of public health, and thereby, perhaps, seek to change how you think about bioethics. I will use smoking as an example, since we do not have much time, and I want to properly convey my message to you.

I recently did some work thinking about possible justifications for banning smoking in open public spaces. For example, you may have seen reports in the newspapers about policies making it a criminal offence to smoke in parks and on beaches in the United States and in Canada. I would like

to argue that maybe these policies can be justified by moving away from the traditional way of thinking about bioethics, and this is what I would like to convince you of this morning.

One way to think about smoking policies is that there has been a gradual movement in order to provide more legal restrictions on smoking. What is interesting about this is that there seems to have been a gradual process. Sometimes the law has brought proposals in response to public demand, but on other occasions legal restrictions have moved ahead of public attitudes, and then those public attitudes have been shaped through response to the legal restrictions. I think that smoking is an excellent example of how fast attitudes may change. When I was first studying philosophy, only twenty years ago, almost everyone would be smoking in a seminar room like this one, and no one would make a comment. But now, the poor smokers among us will have to walk a long distance away from this building in order to be able to smoke. Over a relatively short time, we have seen attitudes transformed and policies that have restricted smoking in various ways have contributed to this rapid change.

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### BIOETHICS WORLDWIDE, ANGUS DAWSON

Attempts to justify policies that restrict smoking fundamentally use two types of arguments. The first one is a harm to others argument. On this view smoking in public places should not be allowed because it harms others, through so-called passive smoking. The second kind of argument is based on appeal to vulnerability, mainly of children, who cannot protect themselves: they cannot make a competent and free choice to smoke or to decide to leave the room when somebody else is smoking, as their parents or others individuals have responsibility for them. (Continuing to raise taxation on tobacco is a very interesting case, because an argument that has proven popular is that this is a way allow smokers to contribute towards the increased health care costs that result from smoking. However, there are some problems with this argument that various health economists have explored, so I'll leave that kind of particular policy to one side.)

Now if we go back to the two arguments, hopefully we can see that a ban of smoking in public places like this building may be justified in terms of the harm that smoking may cause to others. And policies such as removing vending machine from public places like stations, restaurants, or shopping malls, and so on, may be justified as a means of ensuring that children as potentially vulnerable

future-smokers are protected, as they cannot buy tobacco from such machines. Other policies may be justified in the same way, for example, in Ontario, Canada; smoking is banned in cars when there are children present.

Much bioethics, particularly within a North American and European context, tends to appeal to some version of liberalism, often derived from John Stuart Mill's 1859 essay 'On Liberty'. This position has been incredibly influential within bioethics. For our purposes, one of the interesting things about being a liberal along these lines is that it is going to be difficult to reject these arguments, because if harm to others arguments and vulnerability arguments work, then, they can't be used as objections to these restrictions upon tobacco use, assuming that we accept the evidence that passive smoking is harmful, even if it is harmful to smokers themselves as well.

Armed with this background, we can move now to the case that I mentioned before, this proposed ban and in some cases actual ban on smoking on open public places like beaches, parks and town squares. The bioethicist that wants to advocate some version of liberalism appealing to John Stuart Mill's arguments, might argue that such a ban is just going too far because here, there is going to

be no harm to other individuals. The argument might be that this is state paternalism, where state paternalism is always going to be held to be wrong.

As it happens, and I don't have time to go through this now, I don't believe, personally, that paternalism is always wrong; but that would require a discussion of the concept itself. However, let's assume, for now, that it's true. The liberal critic of these policies is just going to say "we can't use the harm to others argument here and vulnerabilit isn't appropriate grounds for a ban either". No one is vulnerable because no one will be being harmed. It might be argued, the liberal says, that smoking is offensive; you might be annoyed or offended by the smoke that is drifting toward you on the beach, but being offended is not being harmed.

So I think that we need to unpack this position a little bit more, and I want to be critical of this argument that I have just presented and suggest that when we think about harm, we have to be careful not to be too simplistic. It is many people's intuitive reaction to this case to accept that just sitting on a bench next to a person who is smoking does not mean that you are going to be harmed, and it is this intuitive reaction that the liberals' argument relies upon.

But I want to suggest that we must ask the question: is that the only harm? Is the direct harm of sitting next to a smoker, and the smoke coming toward you, the only relevant harm that we have to think about? I suggest that this is not true, because many of preferences that we have, the behaviors that we exhibit are actually 'contagious'. We influence other people through our behavior, and if this is at all true, then we can extend the idea of what is relevant when we think of harm here. If smoking is less visible in society, then children playing in open public places like parks, and beaches, town squares and so on, are then less likely to see other people smoking in that environment, they are less likely to consider smoking to be a normal activity, and they are almost certainly less likely to smoke themselves in the future. This idea might be supported by a set of empirical facts about the social influence of smoking. If you have a close relationship with other people who smoke, you are far more likely to smoke. And if you are living in a society where fewer people smoke, you are far less likely to smoke. Smoking might be seen to be contagious where it is accepted as normal within society. If this is true, then could actually think about other people smoking in our society, even in the open, as being a potential harm (through its influence on children's future behavior.

### BIOETHICS WORLDWIDE, ANGUS DAWSON

We can also consider moving to more positive arguments for thinking about banning smoking in public places. Such a policy might appeal to other kinds of values, unlike the liberalism that I've been talking about, which tends to prioritize liberty above all other values. In some cases, liberty will always take priority; in other cases, we just have a very strong presumption in its favor. However, I am an advocate for the idea that we ought to be pluralists about values. On this view, there are a number of different values that are important when we are thinking about policy issues, and ethics more broadly. For example, many people hold equity to be a very important value, and in some cases, equity might be so important that it ought to take priority over liberty.

If you accept my argument that smoking is 'contagious' and the idea that you are influenced (though not necessarily conditioned) by the social situation within which you live, and the number of smokers that you come in contact with, and children, for example, are at a greater risk of becoming smokers if more people smoke, then we can perhaps construct an equity argument saying that banning smoking in open public places is actually the next logical step in a denormalized strategy for tobacco. So, here the focus is not so much on arguments invoking traditional

harm to others, although we may still have vulnerability arguments. The focus is actually upon denormalizing a particular behavior, smoking, which we know is harmful to the smokers themselves, and also to others.

If we now go back to the idea of the Millian grounds for bioethics, the idea of liberalism, and the priority assigned to liberty, we can ask: should liberty be always the value that takes priority over everything else? Are these the only kinds of arguments, the harm to others argument for example or the vulnerability argument, in brackets, can they, are they the only kind of arguments that we ought to think about in bioethics?

Some people seem to think that they are, but I want to argue that we've got no good reason to think that they are the only relevant ethical consideration. And a lot of the work that's been conducted now in public health ethics is trying to explore other kinds of values, other kinds of arguments that can be presented and discussed, as a way for us to expand the discourse within bioethics, beyond just talking about harm to others.

I'd like to end by saying something about global health and smoking. If we look at these figures produced by the World Health Association, we can see that 6 million people die every year from smoking-related disease around the world, and 600 000 of these people are not even smokers themselves. This makes clear that passive smoking does actually make a significant global contribution to early deaths. I wouldn't want to suggest that banning smoking in open public places is the number one priority for tobacco policy, or the most important policy, or the first one in a progressive de-normalization strategy for tobacco but it's the next logical step in moving towards a tobacco-free world, once other measures that appeal to harm to others arguments are in place.

I have tried to argue that if we think about bioethics in a different way, if we think about other kinds of arguments that can be presented, perhaps built around values like equity, and there might be other values here as well, like solidarity, they can be used to justify policies that, otherwise would have to be held to be illegitimate or problematic from the ethical point of view. It would be wrong of bioethics to just dismiss such arguments because they are not well trodden. It is, perhaps, the path that has not been taken before that will lead us to a satisfactory resolution of our ethical issues.





## THE SOCIAL COMMITMENT OF BIOETHICS

### Adolfo Martinez Palomo\*

I consider it worthwhile to spend a few minutes looking back at some of the international work undertaken by Mexican professionals.

No doubt you are all familiar with the Universal Declaration on Bioethics and Human Rights: this is the only document accepted by a United Nations Organization, and has the consensus of over 100 UNESCO member countries. After four years' work, the Declaration was finally declared and – to everyone's surprise – it received overwhelming support; in other words, the document was adopted unanimously.

Dr. Gaxiola has already remarked that these are simply declarative documents, and in this same vein, I consider that bioethics requires a regulatory document to be adopted as a convention. But this would be extraordinarily hard to achieve.

This Universal Declaration took several years because a consensus had to be reached among different cultures and points of view. An agreement was eventually reached because it was a Declaration. Nevertheless, clearly if an attempt were made to establish the content as a regulation, it would prove almost impossible to make progress.

Mexico played an important role in drawing up the Declaration. I'd like to highlight the fact that, before the final version of this Declaration was finished, Mexico's Colegio Nacional held an important meeting in order to analyze the drafts, with participants including Dr. Juliana Gonzalez, Dr. Soberón, Dr. Pérez Tamayo, Dafna Feinholz.

Mexico begun to show its interesting point of view that was important in terms of making progress on the Universal Declaration on Bioethics and Human Rights. This Declaration, as you know, has been followed up with high-profile campaigns and UNESCO has been working on each and every principle upon which the document is based.

Subsequently, in 2009, Mexico held a meeting of the International Bioethics Committee. This meeting addressed a fundamental but complex principle: social responsibility and health. Latin American colleagues participated at this

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### LA BIOÉTICA EN EL ÁMBITO GLOBAL. ADOLFO MARTÍNEZ PALOMO

event, and they insisted on including this principle as part of the Universal Declaration. This led to a period of work, lasting over a year, to draw up a specific document on this matter and which I summarize here because it was relatively straightforward to establish the principles. But putting these principles into practice afterwards is evidently a great deal more complex.

For example, it is easy to speak of access to high-quality medical healthcare, access to proper food and water, improvements to living conditions and the environment, eliminating marginalization and exclusion, reducing poverty and illiteracy. But how do you go from there to public policies? A moment ago, Dr. Dawson presented an excellent example of how to transfer bioethical principles into public policies, in relation to tobacco. In the example I mentioned, we were faced with the challenge of crystallizing general principles into something acceptable as a public policy. Some of these principles are similar to the United Nation's Millennium Goals. As we all know, they were set for 2015 but none of them are going to be met by then because they are extraordinarily complicated goals to achieve.

Therefore, UNESCO has an additional bioethics program known by the acronym MOST (Management of Social Transformations). This program is now the focus of great interest in UNESCO since it tries to popularize general scientific knowledge and, particularly in the case of the social sciences, short-term public policies.

The program seeks to find ways of making general bioethics principles applicable in practice, as well making recommendations that could eventually become norms.

Latin America has several MOST committees. I am pleased to mention that, at the suggestion of UNESCO's Assistant Director-General of Social and Human Sciences, Pilar Álvarez Lazo – a Mexican, as you know – we set up a MOST committee in Mexico in order to analyze some of the principles of the Universal Declaration and to apply them to the field of public policies.

On the one hand, we have been working as a coordinating committee that involves the Science Advisory Council (Consejo Consultivo de Ciencias), the UNESCO, the UNESCO's representative in Mexico, and the Colegio Nacional; on the other hand, there is the work of an

eight-member advisory council (one of its distinguished members being Supreme Court Judge, José Ramón Cossío Díaz).

With the participation of these people – who also represent some of the main social science research institutions – the principle aim is to analyze some of the key issues for public policies, and which relate to core aspects of bioethics and the Universal Declaration of Bioethics and Human Rights.

The objective is to promote in Mexico a culture of design, implementation and evaluation of policies based on evidence. We have been working on this for more than one year, and it has been slightly complicated because we are attempting to achieve practical results in the short term, making it necessary to establish dialogue with Mexico's legislative branch and the executive office of the president, etc. In this regard, we have established some critical routes which are beginning to bear fruit, with the objective of using the analyses by all these expert colleagues in social sciences in order to guide public policies on one of the topics mentioned earlier.

But we clearly could not present every main topic contained in the Universal Declaration to senators, deputies or the presidential office, because this would make it complicated for them to find a starting point.

Therefore we have taken a considerable length of time to define the most salient issues where we would try to make an initial impact. The first topic is migration and bioethics; Mexico is one of the world's busiest migration "corridors", with migrants from Central America to Mexico, from Mexico to the United States, and the reverse migration from the United States to Mexico, of all kinds. Did you know that over forty per cent of doctors graduating in Mexico work in the United States rather than Mexico? This affects everyone from top-level professionals to the least educated workers, and it's a very serious migration problem – and so too is the issue of bioethics and migration.

Our aim is therefore not simply to establish the fundamental bioethical principles, but to be able to make recommendations with the support of a group of colleagues who have an influence in various fields: the media, institutions, and even legislative chambers, always with specific actions in mind.

### LA BIOÉTICA EN EL ÁMBITO GLOBAL. ADOLFO MARTÍNEZ PALOMO

Disability is the second chosen topic. While migration is Mexico's most far-reaching problem, disability is an enormous global problem. The World Health Organization has found that the estimate figures on the world's disabled population have been wrong. Until recently, it was thought that approximately ten per cent of the world's population has some kind of disability; this has now been revised upward to fifteen percent.

This issue gives rise to many questions: What is disability? Where does disability begin?

For many years – as you know – disability was fundamentally seen as a medical issue, but a concept of disability has gradually been developed from a social perspective, hence we now also hear reference to social determinants of disability.

The bioethics of disability calls for a thorough analysis. We must recognize the progress made in Mexico but we must realize that we are tackling a general problem for humanity as a whole, since it affects a large proportion of the world's population.





## BIOETHICS AND INDIVIDUAL RESPONSIBILITY

### Inez de Beaufort\*

Thank you very much for allowing us to be here. It's a great honor and pleasure. I will start my talk with a confession. I have a very unhealthy lifestyle. I will not go into many details but I have written about it.

So, am I morally to blame? Am I deficient in a moral way? Am I stupid? Just a poor addict needing help? Or am I a free person choosing my own lifestyle?

I will talk a bit of some of the different answers to these questions and make some general remarks. The modern rule is, and I will illustrate it with obesity, the modern rule is to lose weight and not to be fat. I am not fat yet, that is the only sin that I have not committed, but if I stay two more weeks in Mexico, I will be very fat indeed, as your food is very good.

We should protect our children, even our pets are too fat. And I think this image shows the complexity of individual responsibility within obesogenic societies. Of course, I do not deny that obesity is a big public health problem. And as you can see, Mexico is second on the world list.

The Netherlands are somewhat down. I am surprised that we are similar to Sweden and Denmark, and that is probably because we cycle so much and because it is so cold and we need all energy to heat up. But it is a worldwide big problem.

All over the world, this is a problem. This is a tiny Chinese child that is too fat.

Responsibility, individual responsibility is often associated with blame, and it is very easy to blame fat people, and they are blamed all over the world. 'You eat too much, so it is your own fault that you are fat.' That I would argue, is far too simple. This is a map showing the different causes of obesity, which are social-economic, individual, physical, psychological, so just note the complexity of the causes of obesity. So, it is far too easy to blame the individual and we all know that we live in obesogenic societies.

Now, obese people are vulnerable to being blamed for their condition. They are therefore desperate for quick fixes and magic bullets. If you scroll the Internet, you can

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see how many crazy therapies are offered to the obese, with promises that are not true at all. It is even possible to sew your lips, but it doesn't look like a very healthy solution to me. Maria Callas is supposed to have eaten an embryonic tapeworm that takes care of your intestine.

So, the 'therapies' offered are often very unhealthy. I do think that governments therefore, should help citizens, because if you don't have many choices, you cannot be held responsible, so it's very important that the healthy choice is made the easy choice. And that the government should spend money and energy and creativity on accomplishing that goal. And I agree with my estimated colleague Angus Dawson.

One of the many popular methods you may have heard of is nudging. That is not prescribing certain behaviors to people, but creating an architecture of choices that will make it easy for them to choose the healthy one. "Mira una manzana" is what I chose at the coffee break. I did not eat it because I wanted to show you that I chose the right thing. But I was very happy that there was also the choice of cookies, so that individuals could choose. I have a short movie, I hope it will run, that in my view is a very funny example of nudge: it is in the metro at Stock-

holm where they turned one of the stairs into a piano stairs. So, if you walk on the stairs you make music. So, people will go and jump on the stairs and not take the escalator, which I think is a very interesting way of inviting people to adapt healthy behavior without all the blame.

Also, there is a problem of publicity. This is a poster from the Netherlands, (a head of a young child put on the big fat body of a man) trying to make parents say 'No!' to their children when it comes to unhealthy food, but it has been very controversial also because so it has been argued that it would stigmatize obese people and obese children.

And despite the effects that such campaigns may have in stimulating healthy choices, I still think that the individual freedom to choose one's own unhealthy lifestyle is worth protecting. Why do I think that? Because I still strongly value, and this may be old-fashioned, freedom. And I am really afraid of governments imposing their views on citizens, not only on obesity or smoking, but imagine imposing views on sexual habits. Let's also think of our drinking habits. Abolition was a long time ago, but we know it was not a great success. One example that you may get angry about is suppose they would have very high taxes on chocolate in order for us to lose weight?

So I enjoy the freedom to take some risks, and I take those risks because they are part of how I see my life and priorities.

Why would I still advice some people to lose weight? Well, I think that the most important argument is to say that it is in your own health's interest to do something. And sometimes, people take risks, sometimes professionally, they have to take risks. You can't be a sumo wrestler and be very thin. I also think that if the government is so keen on health and so interested in our health and well-being, it should first try to work on a decent, fair society where people do have jobs, access to healthcare and access to a healthy lifestyle. So that comes first, I think, before you can blame individuals.

People are also different. What is moral care for one person may be moral harassment for another. And other problem is, what is actually healthy? There are very thin people among you in this audience and I don't want to worry you, but you may have very dangerous fatties somewhere in your intestines whereas slightly obese people may be very, very healthy. It's not only about weight, it is also about fitness.

Is health a new religion? Sometimes I think it is. Would we want to look like that? (Image of extreme bodybuilders.) I do not, definitely. That also creates the illusion of the total makeability of health. My daughter is now on a plane to visit a friend who lives in Brazil who was diagnosed with pancreatic cancer, he is 32 years old and lived a very healthy lifestyle all his life and he recieves such a horrible diagnosis. So, I think we should be careful in spreading the illusion that health is something that you can always control.

So, there is no "one size fits all" argument.

Another argument, may be that people who are obese or who people who smoke have a weak character. That is often used against smokers, for example, and against obese people, they are what I call 'obesinning'. Now, is that so? Are all those famous obese people weak in character, and lacking in virtues? Is it always the merit of the thin that they are thin? Are all these people morally reckless people? (Pictures of famous obese persons.) I wouldn't say so.

It's a very interesting question whether hypothetically, if you could have a pill or a vaccination that would prevent

people from smoking, whether that should be mandatory, or whether if one would find a pill that would just eradicate obesity, that should be mandatory. There are no pills yet, but I'm sure I would buy shares in the company if the company was seriously getting there.

Another argument is that individuals should lose weight because the consequences of obesity are a burden to other people. I have some doubts about that. The interesting thing is that people with an unhealthy lifestyle usually die somewhat earlier than people with healthy lifestyles. And I am not sure that they are a financial burden.

Does that mean that I appreciate people eating all the time? No, this is an image of a hot dog contest, apparently this is very popular in the United States, I have severe moral reservations about it. Not because of the obesity problem, but because of considerations of global justice. Apparently, in the Netherlands, we throw away 2 billion Euros of food, of the value of food, each year, which is almost the same as the costs for obesity, which I think is a huge moral problem, almost a tragedy. That shows us very well that some people do not have access at all to healthy food, while others have too much food, and not of the right kind.

Another issue that I think is really interesting in this particular context of global justice is whether we should eat meat. There are many reasons not to eat meat, and one is that it will increase possibilities for many people who now are close to starvation to have food. That has nothing to do with obesity per se, but it is about ensuring that people have the possibility for a healthy diet.

So, there are many, many different arguments in this debate and it is extremely complex, too complex for the 10 minutes that I was allotted.

So, if like in this cartoon 'nobody drinks or smokes anymore, they just exercise and eat raw vegetables', is that the kind of lifestyle you would want? I would not.





# BIOETHICS: SOCIAL AND SCIENTIFIC COMMITMENT

## **BIOETHICS, CULTURE AND SOCIETY**

Juliana Gonzalez Valenzuela\*

From my philosophical perspective, I consider that, as a general rule, the knowledge of biosciences truly determines our own lives in a number of ways. The fate of what Potter described in 1970 as bioethics is inseparable from the seismic historical shifts in the 20th century, both in terms of science and technology, as well philosophical, political, social and cultural developments.

The advent of bioethics, says Daniel Callahan, can be seen as the main social response to the changes produced in our day; since the end of the 19th century, a series of decisive transformations were already becoming into view. But in particular, since World War Two, these major revolutions began to have an effect – and I wish to make this point very clear – not only on social and cultural affairs, but also on contemporary bioscientific revolutions.

Callahan wondered how human beings should wisely address moral problems, the perplexities and challenges presented by the confluence of enormous scientific and cultural changes of our era. I think that this is the key question. All these changes are having a repercussion, not only on human beings' specific ways of life, but on all our ideas, all our values. In fact, although this is not perceived in the realm of education or in the fields of consciousness, expression or knowledge, these changes or movements are being filtered by society as a whole. In effect, this produces a major upset, a radical innovation in life styles and ways of thinking which affect us all equally. Something is happening to all of us, even though we do not fully know the whys and the wherefores.

In this sense, the most significant facts, in my opinion, are also found in the biological, technological and biotechnological revolutions themselves. In fact we are always thinking about the large-scale movements and the leaps forward in life sciences, but technologies, in their own way, have their own routine and their own historical changes, complementing one another. New technologies make it possible to offer a series of instruments for scientific creation and, in turn, scientific thought generates these states of consciousness and infiltrates so many layers or

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reality that it also boosts technological progress. This involves considering technoscience as part of our historical context and everything implicated by that fact.

However, these technoscientific revolutions alter innumerable concepts that we use and even some of our core beliefs about the life and death of the human bring and of nature itself, just as it creates important changes or impacts our ideas in terms of what can be described as good or bad, just or unjust, both in the present and the future of human history.

In fact, bioethics is not a collection of disciplines but it is truly interdisciplinary in the strictest sense of the word; in other words, an active exchange of multiple disciplines that are in dialog or inter-communication but which ultimately constitute the bioethical discourse, which is key as the appropriate response to the massive problems posed by social revolutions and, in particular, the biotechnological revolution of our time. And doubtlessly, bioethics must respond (as it has done since its origins) to two different but interrelated questions: the serious underlying theoretical problems and the break away from our principle structures to which we had become accustomed before the massive contemporary revolutions.

Given this scenario, we must devise a theory to establish what is solid basis, how to create it, where we can accommodate our new values, our new ideas about life, since a large part of what we can do depends on this theoretical (or cognitive) context of these ideas about the true understanding of man, nature and life itself.

Theory and practice have tended to be dealt with separately, but strictly speaking this is a misguided approach: theory is fed by practice and falls back on it. However, care must be taken with purely practical approach that lacks reflection, knowledge or truths, because ultimately theoretical knowledge looks for truths, and these are what bioethics is searching for, particularly the understanding of the great bioscientific revolutions of our time.

Of course, there was Darwin on the one hand and Mendel on the other at the close of the 21st century, but in our own world and our own time, we are re-encountering the Darwinist awareness that human nature is the result of evolution, that we are simply the latest episode of an evolutional process that began with proto-cells and which has been progressing and changing over the course of this strange history of change, of evolutional development which is infinitely larger than human history.

This gives rise to us being able to recognize ourselves as monkeys, as proposed by one of our Darwinist authors, Francisco José Ayala, on the basis of the question and title of his book, Am I a Monkey? Apparently of little importance, this has somehow taken away our sense of security of being another type of being, somehow different to the rest of the animal kingdom. Man previously occupied a privileged position in the cosmos, but as we become aware of the possibilities of Darwinian evolution and evolutional biology, the very foundations of position have been eroded.

And even when reactions are immediately forthcoming, we must rescue the human from the man, when confronted by the threat of this "animalization" of everything that it means to be human, by the loss of those laws that regulated our behavior and that are now simply victims of natural selection: we are exclusively beings motivated by natural selection.

But that is nothing compared to the moment when it is also discovered that we are an acid that managed to penetrate the very center of the vital cell, a deoxyribonucleic acid; in other words, we are simply DNA, we have a pre-configured structure that we share with bacteria, worms, with everything,

because DNA is universal, it's the structural form used by life to remain as the possibility to continue, to become life and diversity in all the different possible ways.

But then what part do we play in all this? We are structured beings who carry with us an inscribed code or law about our species, our community or population: in fact we are vitally structured by this special acid, which is the same as that carried by every other living being and yet we are different, because each of us has something different, which nevertheless does not separate us from our natural reality.

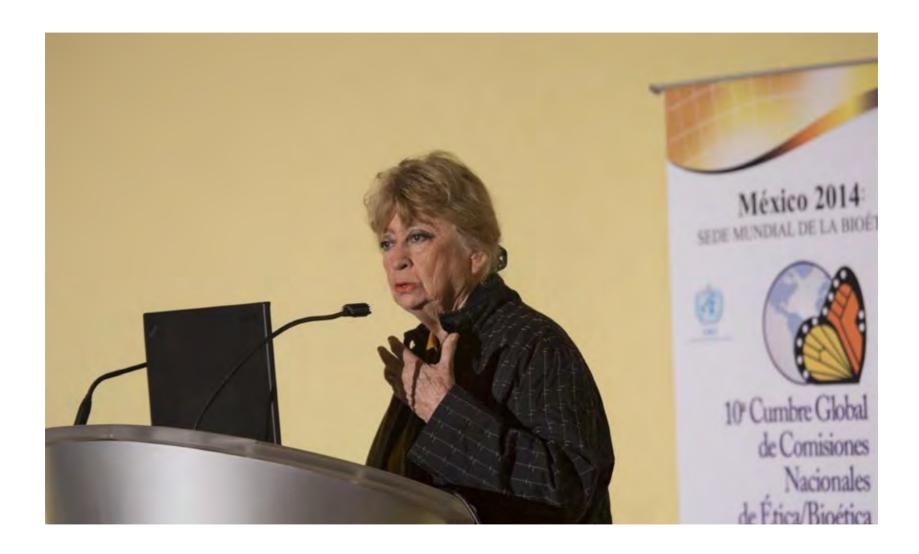
Finally, we have the third great biological revolution: neuroscience. Here the revolution is not simply in the change taken place, in the strict sense of the word, with genetic or genomic conscience, but what happens now to the neuro-cerebral conscience, the awareness that we are the neuronal man, as may be the title of one or several books: it is the recognition (already found in Hippocrates's work in the 5th century BC) that our brain is what thinks, feels, desires, loves, hates. In other words, all our passions, ideas, values are a mental state, a neuronal encounter with our own reality.

Our break away from the foundations of an entire tradition is undeniable; this points to a rupture of dualist conceptions, in which we are no longer body and soul, we are no longer the animal being and the being that comes from divine creation, and we have even been put on a similar rung as the monkey, without this necessarily being an offensive comment: the point is that we are no longer on firm ground, and this has changed an entire system of beliefs. Essentially this is the realm of what has been called, is called, and will continue to be called, bioethics.

Why the sudden boom in bioethics around the world? Why has it grown exponentially? Why are we all involved in bioethics? A little over thirty years' ago, only a few of us were referring to the concept, but now the whole world is engaged in bioethics. What does this mean? It means we must construct the discipline that is destined to combat every crisis, from the very foundations of our thought to the more specific and definitive facts relating to the taking of a clinical or vital decision (such as deciding whether or not to have an abortion), and which also passes through the reflection of the world's most important conceptions about whether we are truly simian, if we truly do not have anything specifically of our own, and what role ethics plays in all of this.

But where is the ethics? Do monkeys have ethics? Is it not, rather than ethics, more a question of prolonging the same moral differentiation that animals have in one way or the other? This gives rise to countless problems on a theoretical, axiological, cultural and social plane; therefore bioethical problems are not commensurate and it is not only those of a practical nature that are dealt with or must be solved by committees on bioethics, in hospitals and in schools: there is a reality of bioethical decisions at a practical, almost universal level, which must be dealt with, but without leaving aside the major philosophical questions.

In that sense, we must ask ourselves again: What is nature? What is human nature? What is life? These are questions that form part of the ethical-philosophical dimension of bioethics, because this philosophical reflection within the theoretical realm cannot exist without that practical and concrete task: we must never lose sight of the link between both parts, where a bioethics of knowledge and a bioethics that sets problems and that seeks primarily to be science that provides possible criteria, principles and values of bioethics. The road ahead is a constant to-ing and fro-ing between both positions: this is the bioethics that I believe must be developed everywhere and in every discipline.





### **EMERGING BIOTECHNOLOGIES**

## David Koepsell\*

I was asked, and first of all I want to thank Dr. Chavez and Dr. Kawa for inviting me, at this great occasion and in the company of such great speakers. I was asked to speak about bioethics and emerging technologies. And I think that in many ways it ties together all of the other talks we've heard today.

And it addresses some issues that I think, show that at the center of this, at the center of the questions that we have been discussing in bioethics, are many, as many people have mentioned today, are many unanswered issues in philosophy and in ethics in particular. And I want to start with these core bioethical principles, because it illustrates a trend. A developing trend that we have seen in applied ethics. And that is that we have seen a sort of recursive tendency to go back to basic at the co-principles that preceded what we call applied ethics.

So we know, most of us here know, the history that brought us here. How are some very public and despicable acts the current regimes of applied ethics began with medical ethics. And the Nuremberg principles form the core of what is now what we call now the bioethical principles annunciated in the Belmont report and in the Helsinki declaration.

But the first interest on issues of applied ethics focused on human experimentation. And over time, we have seen the development of something that we now call bioethics. Now, for somebody trained more broadly in philosophy or in philosophical ethics, many of us are familiar, and I am sure that my colleagues, the bioethicists, are familiar with conflicts or tension between theoretical ethics and applied ethics. And in many ways for the past fifty years those who do applied ethics are somehow treated as dirtying our hands. And theoretical ethics is seen as the real intellectual philosophical pursuit.

But I hope to clear that notion and show how bioethics and what has emerged in the past 50 years of bioethics, now form a platform that looks to transcend current bioethical issues. So bioethics adopts and expands upon the principles of medical ethics and includes such issues as animal ethics, tissues and organs, reproductive rates, genetics, cloning, euthanasia, and a number of other important new rounds that we now discuss in our bioethics classes,

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and that concerns institutions and public policies. But there is a new trend and that is what we want to talk about. I teach in an Engineering faculty now and I teach ethics to engineers, so my background in bioethics at first might seem to be tangential or orthogonal.

I think that what we see with the development of new technologies, is that we have two parallel trends, one in the realm of applied sciences and one in the realm of applied and theoretical sciences. So converging technologies is the term that we use to describe a tendency in new technologies to begin to start to look like one another. And the technologies that we can think of moving in this direction include engineering, nanoscience, biology, and numerous other fields in the sciences.

So this is a term you may or may not have heard of, but it appears to illustrate a general tendency in technologies now to start to overlap in the way that they didn't overlap before. So, what does this imply for bioethics?

So, here are some...they appeared to be science fiction examples but in ethics one of our tasks is to look to the future and predict what may happen so as to avoid the mistakes that we made in the past when new technologies confronted us and we had not appropriately considered their ethical implications.

These are things that people are now interested in doing, and that people are not only interested in doing but people are beginning to do. Or to at least consider doing.

So one example is uplifting other species. Dogs are perhaps an outlandish example, but consider the apes. If we are capable of doing some genetic engineering on apes to have the capability of speech, then this poses a significant ethical quandary. We use apes in ways that we wouldn't use our fellow apes in this room. So we would be forced to reconsider our notion of what we ought or ought not to do with our genetically engineered talking apes.

A little less science fiction is the question of new materials that we can create through synthetic biology. Synthetic biology is one of these great converging technologies that really does bring together questions of not only genetics and genomics, but also engineering sciences and ultimately the goal of sort of creating biofactories. So, real, practical experiments being able to engineer new materials using synthetic biology treating as building

blocks what only nature has until now, used as the building blocks of life. It is a real question in ethics and bioethics. And it also shows how the field of engineering is beginning to converge.

My university, the technological university of Delft, we don't do any animal or human experimentation in traditional ways. We do have a synthetic biology lab where people are engineering new sorts of life forms to create things for us. Obviously this would be extremely useful as a sort of shortcut to nanotechnology and it seems very promising.

We may also consider questions about artificial intelligence using biological media. So, people have already done this, they have created memory storage circuits using neural cells. This is biological material. Is this a question for bioethicists to consider? Or is this an engineering problem? Should only engineers worry about this?

I believe that these sorts of technologies are illustrating not just the convergence of technology but the reconvergence of ethics. So in many ways, and I think it is legitimately disturbing, bioethicists or theoretical ethicists, we have seen a sort of fragmenting of applied ethics, so there is neuroethics, nanoethics, synth-ethics, bioethics, but converging technologies really offer us an opportunity then to reconverge these various fragmented fields of ethics. And bioethics leads the way because it is the best considered of this field.

And then a final example I have brings in two questions, brings into ethical consideration some other social issues, issues of social justice for instance. Real work has been done in longevity, and some people believe that immortality is around the corner if we only figure out the right steps.

Well, these are not just bioethical issues. These are issues of social ethics, broader issues are involved, if some of us can afford to live forever, as long as social security may last forever, that is a real problem for those who can afford it. But I think this is an issue of social justice as well. And there are also, clearly, bioethical issues.

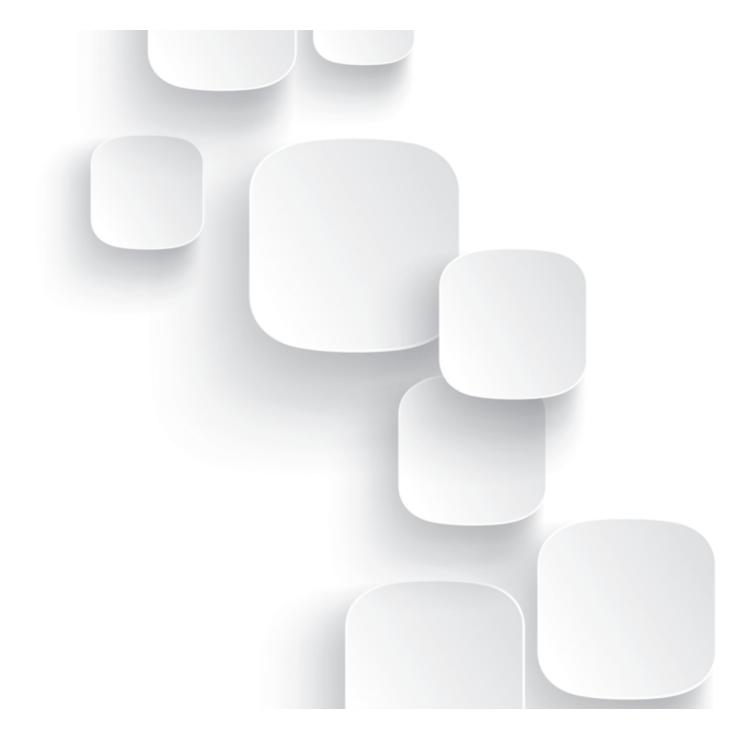
So, what I think we need to consider is how bioethics may lead the way for us to reconverge all of the various fields and fragments of applied ethics. Reconsider whether or not the three or four principles from the Nuremberg code are sufficient to deal with these sorts of issues we will face with these emerging technologies?

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And then also revisit some very important foundational questions in ethics. Are there foundational principles that can be applied objectively and universally? And this is sort of a matter for theoretical ethicists, because this is still an unfinished work for ethics in general, but it is a challenge that we face with converging technologies and converging applied ethics.







## BIOETHICS AND SCIENCE: GENETICS AND NEUROSCIENCE

## Ricardo Tapia Ibargüengoytia\*

What does the link between bioethics and science mean? I submit that every bioethical problem currently facing us has arisen from scientific progress, especially in regards nature, because prior to this knowledge, the solution to ethical problems was based on what "God said about how this or that should be done," leading to interpretations about right and wrong. But in those days we had not come across problems such as the phase of embryonic development, abortion, euthanasia, cloning, organ transplants, neuroethics, etc.

The evolution of species and the DNA structure is one of the most significant areas of progress and has altered the future course of ethics and human behavior, as already mentioned by Dr. Juliana González. This has been absolutely revolutionary because now, as Juliana says, we must consider that the human species is just one more species on the planet and that all of its functions depend on that fact, thus altering the concept of "human nature" and what this entails for human dignity.

This extraordinary progress cast doubt on the definition of the human being as a privileged species or one created out of nothing, essentially different to the rest of living creatures: light was shed on the unknown biological nature of man, since it is based on a DNA structure, as found in all living creatures, that contains genes and information for synthesizing the proteins that are characteristic of the human species; in this sense, there is about a one per cent difference between the human and the chimpanzee's genome.

Recognizing this fact, which defines humanity simply as a product of biological evolution, profoundly affects the concept of human dignity, particularly in reference to the organism's cellular origin, the product of the fertilization of the ovum by the sperm, the human zygote. The blurry concept of human dignity is neither biological nor scientific, but ideological or, if you will, philosophical, and to back it up you must refer to the "spirit" or the "soul", concepts that do not sit comfortably in scientific nomenclature.

The human brain, the cognitive organ, was developed in the course of this biological evolution; I refer to our

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consciousness, the most human of characteristics, as André Vesalio wrote in the 16th century. And, according to Claude Bernard three centuries later, from a physiological point of view, the underlying metaphysical phenomena of thoughts, consciousness and intelligence in the various manifestations of the human soul are shared vital processes and can only be the result of the function of the organ that expresses them and, in this case, that organ is the brain.

On this basis, the brain's functions are those that define our mental health and everyday behavior, much more directly than our genes. Our new understanding of physiology and biochemistry of neurons, neural networks, specific functions of the cerebral regions and the various neurotransmitters, have opened up a new panorama to understand the brain's functioning and consciousness. Recent non-invasive techniques to visualize the activation of cerebral regions in humans offers unsuspected possibilities for analyzing mental functions.

Therefore, every act, every moment and every word does not depend on genetic structure – since the formation of our brain depended on that – but on the functions of hundreds of thousands of millions of neurons which make up our brain. Of course, this has created a whole new range of ethical problems, something that was hard to imagine just 60 or 80 years ago, since at that stage we did not yet have much knowledge about how the brain worked

This has led to a new sub-discipline or branch of bioethics, known as neuroethics, focused on addressing ethical and social problems derived from neuroscientific understanding of the brain's functions, since these control people's behavior, consciousness, personality, free will, drug use and addiction.

Hence this new branch of knowledge looks at ethical and social problems arising from these possibilities. Equally, in tackling aspects of human behavior, neuroethics is closely related to laws, because these are ultimately concerned with a certain regulation of society's modes of behavior.

However, now we know that millions of neurons that form our brain are formed and organized into perfectly established, genetic circuits (such as those in the cerebral cortex) and that the communication between one neuron and another depends on what is functionally a chemical-molecular type of structure called a synapse.

In each one of the thousands of millions or trillions of messages between the neurons, a chemical substance is released from a terminal and acts on the next neuron, activating or suppressing it; this is multiplied by the number of neurons and the number of connections that a single neuron can receive from other ones, producing a figure than makes even astronomical data seem insignificant by comparison.

But these scientific advances are already posing a series of problems that are also derived from new technologies: How do we handle psychopharmacology? What is brain death or heart failure? These and many other questions also have enormous repercussions on legislation.

In this area, we can genetically modify one component of the chemical synaptic transmission, as we currently do with mice, a very common procedure in biomedical research: you can modify one molecule or one part of a molecule that is related to the neurotransmission in order to modify its behavior. This modification allows these mice to remember for longer and more accurately a type of behavior for which they have been trained.

We have always been able to alter human behavior through drugs (used for millennia) or alcohol. But this scientific knowledge has now allowed us to understand that we can alter communication between neurons, as well as each one of these biochemical steps and this communication between them. And this, then, already presents a series of questions about how we can use drugs: To "improve" memory, for example, to treat Alzheimer's disease? To "improve" regular brain function? What is the type of memory that could be improved? Is it permissible to improve the brain's functioning, even when there is no disease to treat, to improve memory (and, therefore, intelligence), or to accelerate the development of cognitive functions?

Of course the first thing that comes to mind are the uses made of all drugs with effects on the nervous system: anti-depressants, anxiolytics, soporifics, anticonvulsants, and those used to treat neurodegenerative diseases such as Alzheimer's, a disease that causes loss of memory, intelligence and some mental functions. But what about when these drugs are used not to treat diseases but to improve mental functions?

Many of the drugs that are used clinically, such as Ritalin, used for hyperactivity disorders in children, have serious effects in this regard; Modafinilo, which sold US\$700 million in 2008 in the United States, is used in ninety per cent of cases by healthy people and students to help them learn and improve their grades: these drugs are still sold without a need for a prescription, unlike these which are prohibited and illegal. Therefore, drugs such as those mentioned above can have positive effects or negative effects (in the case of illegal drugs).

These aspects of neuroethics has therefore become the subject of many studies and articles, such as the responsible use of drugs, thus posing an important ethical and neuroethical problem, in terms of the proper management of drugs: this is one of the problems facing many societies, and Mexico in particular, giving rise to a broad debate that has existed for some time already but which has now come to the fore: How do we handle prohibited drugs and the possible legalization of some of them?

In this debate, I consider that legislators much take into account the precise scientific knowledge in regard to the possible effects on human behavior. In this regard, we already know which neural circuits are related to addiction,

and although our understanding is not yet complete or total, we do know (even at the level of the molecules involved in the neurotransmission) how addiction can be produced.

Data exists that indicate an increase in the number of molecules that recognize a specific neurotransmitter when an addiction is produced, and it is this neurotransmitter which participates in the neural circuits related to pleasure, gratification, with the sense of wellbeing: from a molecular point of view, we have already begun to see that what it means to be addicted to a drug. Therefore I consider that all these new areas of understanding must be duly considered by those who take decisions about whether to continue criminalizing addicts of an illegal drug simply because that drug was prohibited, and also since they can be treated for their addiction, in terms of the drugs that alter their behavior.

In conclusion, all this scientific knowledge is causing these ethical dilemmas, requiring a change in the analysis of how to legislate to regulate human behavior and allow societies to work better. To prohibit drugs as a blanket measure is not sensible, since their consumption is steadily increasing despite prohibition. Therefore we

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need other, more ethical methods, based on scientific knowledge, to regulate behavior for the benefit of the individual and society as a whole, seeking to cause the least possible harm in every social group. Science cannot be ignored when it comes to legislating matters that correspond to the personal conduct of individuals in a society that respects human rights.





## SCIENTIFIC MISCONDUCT. A GLOBAL, AGE-OLD PHENOMENON

# Sergio Litewka\*

Less and less attention is paid to scientific misconduct and its consequences. In fact, malpractice and fraud in scientific research is not a recent phenomenon. Some argue that even Louis Pasteur must have had serious discrepancies between his laboratory notes and his publications on anthrax and rabies, a fact that, considering that the scientist had been awarded 10% of the funding provided by the French government, nowadays would fit perfectly within the definition of scientific dishonesty.

In 1916, the British Medical Journal (BMJ) published an article written by the US doctor, James Shearer, who served in the British Army during the First World War. Shearer was attributed with discovering a device to study the gunshot wounds of soldiers; he called it a delineator and he claimed it gave more accurate results than X-rays.

After initial enthusiasm had subsided, this so-called delineator was found to be useless. Up to this point, everything might have simply been the product of the physician's over enthusiasm, but, unfortunately for him,

later investigations revealed intentional fraud in the description of the equipment's operation and its supposed benefits.

The BMJ was forced to publish a retraction and to report on what had happened. This is probably among the first ever retraction in the history of scientific publications. The result for Shearer was disastrous. He was court martialled and sentenced to death by firing squad, on the charge of committing fraud against the British Armed Forces. Eventually, his sentence was commuted to serving time in prison, and Shearer ended his days behind bars.

In principle, a distinction must be made between what is considered scientific misconduct and abuses of subjects or animals used for experiments. This distinction is clearly artificial and primarily originated in the need to define comparable situations, at least from the perspective of highly eloquent moral intuition but which, when transferred into the world of laws and regulations, usually become more blurred than is desirable.

<sup>\*</sup> International Program Director of Ethics Education and Research Ethics at the University of Miami.

Obviously, any scientific study that lacks a rigorous statement and methodology, that is based on a cruel or negligent use of living creatures, that has not sought consent from the subjects of the experimentation, or that has used deceit to obtain this consent, is an example of unethical scientific conduct. However, a dividing line exists, possibly artificial but necessary nonetheless, in order to define different situations, distinguishing unethical research and scientific misconduct.

In the year 2000, following a series of scandals (it is a fact that regulations of scientific research, whether these concern abuses of human beings or researchers' misconduct, are always fuelled by scandal), the United States' Office of Research Integrity (ORI) tried to simplify the criteria which had it has hitherto been using to conceptualize scientific misconduct, defining the lack of scientific integrity as ... falsification, fabrication or plagiarism in proposing, performing, or reviewing research, or in reporting research results... This definition was carefully to specify that research misconduct does not include honest error and differences of opinion...

It was also clarified that, to find a researcher guilty of what is considered scientific misconduct, requires a significant departure from accepted practices of the international scientific community, and the misconduct must be committed intentionally, or knowingly, or recklessly and that the allegation be proven by a preponderance of evidence.

This aspect is key, because there must be intention for scientific misconduct to exist, according to the ORI. Therefore, mistakes derived by incompetence or ignorance would not be considered as lacking integrity. On the other hand, European Union countries, Canada, the United Kingdom and Australia do not seem to distinguish between the intention to mislead and the error resulting from ignorance.

At the turn of this century, a conference was held in Edinburgh in order to establish a consensus in the United Kingdom for a more accurate definition of research misconduct, reaching the following conclusion: behaviour by a researcher, intentional or not, that falls short of good ethical and scientific standards. Therefore, errors through negligence or technical ignorance are as serious as those committed with the intention of committing fraud in research.

However, in the same way that definitions are not straightforward when trying to set framework parameters for what constitutes scientific misconduct, there may be cases when, once such misconduct has been identified, the necessary structures to prevent it and penalize it are lacking, or no proper process is in place to research the complaints. This is even more evident in developing countries, where academic or research organizations often receive money from developed countries to carry out joint research, but far fewer resources (if any exist at all) are assigned to prevent misconduct.

You could refer, for example, that in a country considered to be developed, such as England, at the end of the 1990s, between 60 and 100 cases were reported each year. These figures continue to grow and many believe they are just the tip of the iceberg of an extremely serious situation, the consequences of which are beginning to be felt.

A report recently published in the *United States' journal Proceedings of the National Academy of Sciences*, surprised the profession by revealing that in a review of 2047 indexed research articles that had been subsequently retracted, only 21.3% had been as a result of "honest

mistakes." The rest had been retracted due to factors attributable to misconduct, such as fraud or suspected fraud, duplicated publications or plagiarism. The retracted studies had been mostly carried out in the United States, China, Germany, Japan and India. No country in Latin America was mentioned in the report.

What do we know about scientific misconduct in Latin America?

At first sight, the lack of references to scientific misconduct in the region appears remarkable. When cases do exist, plagiarism is generally cited as the most frequent cause and, more surprisingly still, the difficulties facing the researchers to link plagiarism to misconduct.

There are many reasons to explain why Latin America lags behind in identifying a fact that is certainly a global phenomenon. In principle, many studies from the region are published in Spanish in local magazines that are not necessarily indexed and, even when they are, are not always consulted by those who do not understand the language. Also, compared to the so-called central countries, in this region scant resources are assigned to produce scientific knowledge. In fact, apart from Brazil (with

just over 1% of its GDP), other Latin American countries budget less than 1% of their gross domestic product to support scientific studies.

Misuse of public funds is cited as one of the reasons behind the efforts made by regulators and legislators of those pioneering countries to identify and attempt to prevent scientific malpractice. The fact that a large proportion of researchers (at least in the field of biomedicine in Latin America) are funded by the private sector might explain the lack of interest displayed so far by those who should be working to identify, prevent and correct a problem; as we have said before, we do not yet know the true size and regional importance of this phenomenon.

We must also refer to the disconnect between teaching and reality. Latin American universities are working harder and spending more time on educational programs that propose to stimulate responsible research conduct. This is partly because a firm belief exists that an academic education is incomplete without teaching that essential ethical frameworks must be observed when generating knowledge; partly because globalization has aided a level of collaboration between universities which, before

the communications revolution, was unthinkable, hence these exchanges demand clear and transparent rules for all participants.

But there is a gap between theory and practice, perceived in particular by young students and scientists who must often conform to established practices. They must, for example, share authorship credits for their work with mentors or other, older researchers in order to be able to continue their professional growth within their organization. This is especially the case since they understand that, even if they were to decide to complain, the institutional mechanisms to take forward their complaints are scarce and insecure, and they could even jeopardize their career.

The "ethical climate" in some countries is no less important. With the perceived problems of widespread corruption existing in other aspects of daily life, it would be naïve to think that academic organizations can remain on the sidelines of situations affecting the nation. In extreme cases, a type of "moral anesthesia" can come into play, meaning that conduct which in itself could be relevant (such as plagiarism or covering up blatant conflicts of interest) pales in comparison to situations in which violence, the lack of an independent system of justice, or daily abuses are the norm in citizens' lives.

Much work still needs to be done in the field of scientific integrity in Latin America. Possibly the first step has been taken to diagnose the situation, to determine whether a problem genuinely does exist. And if it does exist at least on the same scale as the problems reported in industrialized countries, which is more than likely, then what would be the strategies implemented in order to prevent and, where applicable, to impose the appropriate penalties.

Education is one side of the equation, but only one. It must be understood that – over and above legal norms and confusing articles and decrees – trust is the keystone for scientific research. This trust is essential, not only for those continuing their studies or trying to apply the conclusions of their published work, but also for the general public.

To shore up this trust, institutions where scientific studies are carried out must develop the necessary tools to research allegations of misconduct; editors (certainly, conclusions that were never published, have never existed) must be custodians of the process of selecting works submitted to them for publication; reviewers or referees of these articles must have sufficient freedom of criteria, lack of bias and knowledge to be able to collaborate in this

selection; and scientific and general organizations must have the appropriate regulatory powers to penalize those it has found violating ethical norms.

In this context, in regards biomedical studies with human beings, bioethics commissions play an essential role. In principle, these committees for research ethics must have the proper resources so that their members are properly trained to make them capable of responding as soundly as possible to the growing demands placed on them. Commissions are the first organizations to evaluate the ethical framework of studies using subjects for experimentation. But apart from their specific tasks, national bioethics commissions are essential as advisory organizations for political and regulatory decision-makers. Therefore it is feasible that these commissions have an increasingly important role in contributing to fostering the processes that sustain academic integrity.

It is a complex challenge for an even more complex world. As far as we know, nowhere offers infallible answers. Nor will any such place ever exist. As in every human activity, dishonesty is a deep-rooted possibility within the academic world and tackling it requires a range of strategies but above all the will to confront it.







# **CLOSING REMARKS**

## Dr. Manuel H Ruiz de Chavez

The National Bioethics Committee recognizes bioethics as an expression of ethics that reflects, deliberates and makes proposals for regulations and public policies, to regulate and to resolve conflicts in society, particularly in the development and application of life sciences, as well as in medical practice and research, which affects life on the planet, both now and for future generations.

To make progress in the culture of bioethics in Mexico requires dialogue and reflection on major issues for society, health, science, innovation and technology.

For this reason, we have with us today academics and scientists, well-known figures from the world of politics and society in general, discussing fundamental issues on which they work every day, and making contributions based on their experience and knowledge. This brings within our immediate grasp various expressions regarding the meaning and scope of bioethics and its application.

#### CONTRIBUTIONS

After listening to our speakers, we now have clear ideas about the importance of acknowledging the progress that has led up to this present moment, resulting from the pioneering work of those who first promoted bioethics in Mexico.

The events to which we refer as part of the launch of Mexico as the global venue for Bioethics in 2014 will make it possible to spread the culture of bioethics and improve our understanding of new, global and multinational perspectives.

We have seen the importance of being aware that the impact of ethics on science is translated into scientific integrity and that the social practice of ethics is a consequence of democratic freedom.

In the same way, in terms of setting health priorities, the importance of bioethics lies in recognizing the factors that determine it, examining its consequences through a

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different lens, from the perspective of values and ethical principles, which will support and make feasible morally acceptable social interventions.

In regard to strengthening the legal framework of bioethics, health has developed from being conceived as a constitutional right to becoming a fundamental human right. The State therefore must guarantee that all Mexican citizens have access to healthcare, inspiring us to adapt bioethical imperatives corresponding to this development, and linking legal norms established in Mexico with the international framework as we are required to do.

In education, bioethics poses no less of a challenge, especially since bioethics is not a traditional discipline but seeks to achieve interdisciplinarity and to develop its own study methodology.

Globally, an increasingly pressing social need exists for public health policies given society's demands and people's responsibility for their health; therefore, public policies must be reflected through bioethics and not through a simplistic analysis of damage to society. In the context of the social commitment of bioethics, since the Declaration of Bioethics and Human Rights, Mexico has been developing various measures and studies jointly based on social and work commitments.

Therefore, two issues have been promoted through bioethical analysis in order to apply each of the Declaration's principles: the Bioethics of Migration (Central America-Mexico-Central America) and the Bioethics of Disability. Both issues require the efforts of citizens and the application of the constituent public policies.

In terms of individual responsibility, given that this is not an isolated responsibility but one that is implicit in social reflection, assuming it is subject to various actions and policies that have an impact on the personal choice of a personal, healthy lifestyle.

From a socio-cultural standpoint, the idea that encompasses theory, bioethics, society and culture creates a flow of multidisciplinary approaches that must lead to individual and collective action. Bioethics, as we have indicated, is inseparable from the major historical changes of the 20th century in every field, as well as the great scientific revolutions of our time. The effect has been so profound that it has led to a transformation in ways of living and thinking.

The concrete practice of bioethics must be nourished, as correctly remarked earlier, to ensure that philosophical questions continue to be asked, thus enriching every area of its implementation.

From a social perspective, we must rethink the analysis of reproductive rights, genetics, cloning, use of organs and tissues, ethics in regard animals, bioethical principles expressed in terms of wellbeing, justice and autonomy.

In the confluence of the sciences – such as engineering, nanoscience, and biology – bioethics must play a key role in understanding phenomena such as artificial intelligence and the prolongation of life.

On a scientific basis, neuroethics, ethical problems derived from our understanding of the brain's functions, as well as the concept of responsibility involved in connection to these areas of knowledge, bioethical understanding is required in the same extent that science cannot be ignored when it comes to legislating on matters corresponding to the personal conduct of individuals in a society that respects human rights.

This is a brief recap, by no means exhaustive or detailed, of the contributions made today, which have certainly enriched our perception of bioethics and offered us new spaces for reflection.

Perhaps we have left pending the issue of bioethics in regard to chronic and degenerative diseases, the scourges of our era. Mexico today is faced with the bioethical challenge of reflecting on diabetes, cancer, obesity and arterial hypertension, as well as cerebrovascular diseases.

## **ENDNOTE**

I hereby declare the conclusion of this Symposium's work, and it only remains for me to give my thanks for all these thought-provoking papers on bioethics presented in the run-up to the 10th Global Summit of National Ethics/Bioethics Committees and the 12th World Bioethics Congress to be held in 2014, "Year of Bioethics in Mexico."





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