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科学及文化组织

European Commission- UNESCO Conference: Joint Action for Capacity-Building in Bioethics



JACOB

CONFERENCE REPORT

Mexico City,
26 –28 November 2009
Sheraton Hotel, Centro Histórico

Introduction

The European Commission - UNESCO Conference: Joint Action for Capacity-building in Bioethics (JACOB) was organized by UNESCO with financial support from the European Commission, and held in Mexico City, Mexico, on 26-28 November 2009. The event brought together more than 100 participants representing national bioethics bodies, as well as regional and international organizations working in the field of bioethics, to share knowledge and experience on establishing and operating National Bioethics Committees (NBC), and to reflect on ways to improve collaboration in the future.

The main objective of the Conference was to facilitate working linkages for knowledge and experience sharing between NBCs from around the world, as a step towards reinforcing bioethics capacities of countries that have recently established, or are planning to establish such national bioethics bodies. UNESCO derives its mandate to work with its Members States to bolster their national bioethics infrastructure from the Universal Declaration on Bioethics and Human Rights (the Declaration), which, in article 19, states that “independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level”. This Conference, together with the follow-up activities, was designed to make an important contribution to building national bioethics capacities of countries around the world, for them to be at the forefront of protecting human rights against the threats or challenges posed by scientific and technological advances.

The JACOB Conference was held immediately after the Sixteenth Session of the International Bioethics Committee (IBC) of UNESCO. The back-to-back arrangement of the IBC session and JACOB Conference aimed to take advantage of the opportunity for synergy and promote exchange of experts, ideas and knowledge between the two events. Since many of the IBC members available for facilitating and leading discussions during the JACOB Conference have served on ethics advisory or policy-making bodies of their respective countries, they offered the participants of the JACOB Conference a valuable real-world insight into practical issues of running the Committee.

Opening of the Conference

At the opening of the Conference, Mr Pierre Sané, Assistant Director-General of UNESCO for Social and Human Sciences welcomed the participants and stressed that addressing emerging social and ethical challenges is one of the overarching objectives of UNESCO. Through such initiatives as Global Ethics Observatory databases (GEObs) and Assisting Bioethics Committees (ABC), the Bioethics programme of the Social and Human Sciences Sector is endeavouring to enhance national capacities of Member States for regulating, reviewing and addressing ethical issues related to science and technology.

In his welcoming speech, Mr Pēteris Zilgalvis, the Head of the Governance and Ethics Unit, Directorate Science, Economy and Society at DG Research of the

European Commission, emphasized the role that shared values play in the activities of the European Union, as reflected in the existing policies to attain the highest ethical standards with regard to health care, science and research. He noted the pressing need for a more global dialogue and collaboration on issues of ethics of science and technology, particularly bioethics, stemming from the reality of globalization of science and scientific research. The present Conference, according to Mr Zilgalvis, was an excellent opportunity to plant the seeds of further international cooperation in ethics.

Presentations from the Members of National Bioethics Committees

During the first session, speakers from the newly established national bioethics committees shared their experiences about the processes that have led to the establishment of NBCs in their countries and about the challenges they face after the official inauguration. The second session featured speakers from Members States that are in the process of setting-up a national committee. The third session was dedicated to presentations from the representatives of well-established national committees, with emphasis on good practices and lessons learned during the operation of their committees.

The presentations and debates revealed a number of interesting questions that every bioethics committee has to consider from the beginning of its existence, especially the ones concerning the concepts of independence and pluralism.

In regards to independence, the participants analyzed the available modalities of establishing and financing a committee and its secretariat that make it least susceptible to undue influence from the appointing agency or the government. Several participants asked if a committee that is financially sustained from a government agency, such as a ministry, can truly be independent and free from governmental interference in its work. It was largely agreed that regardless of the source of funding, independence is earned through day-to-day activity of the committee, through the high quality of its work, and the personal integrity of its members. In this regard, it was noted that establishing NBC by a legislative measure enhances its independence both at the theoretical and practical level. However, as some participants remarked, a different set of challenges arise in regards to establishing independent national commissions in non-democratic countries.

As for the issue of pluralism, the participants pondered over practical and theoretical limits of the concept. To what extent can the pluralistic composition of the committee guarantee the representation of all relevant viewpoints? Perhaps more importantly, should every voice be heard during the deliberation, even those who directly challenge the basic human rights principles underlying bioethics? Participants agreed that since the number of views represented in NBC membership can only be limited, and therefore will never be exhaustive, it is the duty of committee members to include in their deliberation the relevant, yet non-represented perspectives. Most participants also thought it essential that the argument set forth by the committee be informed by the plurality of reasonable

views. However, all who engage in the debate should share the commitment to a reasonable debate and be prepared to adjust or even change their views based on deliberation.

Multidisciplinarity was noted as another defining characteristic of a successful bioethics committee, which helps the organ to engage in the broad scope of issues under the Bioethics rubric. Moreover, in order to have the capacity to deal with a wide range of bioethics topics elaborated in the Declaration, it is crucial that the committee maintains flexibility to invite external expertise on ad hoc bases, as required by the topic of deliberation.

Building Bioethics Networks

The fourth session of the Conference, on building bioethics networks, featured speakers from the organizations that represent existing regional and international networks, such as the European Group on Ethics in Science and New Technologies of the European Union, Steering Committee on Bioethics (CDBI) of the Council of Europe, The Forum of National Ethics Councils (NEC Forum), European Commission, and the World Health Organization.

The session aimed to examine the existing bioethics networks in order to enrich the discussion on stimulating further global collaboration between national and regional bioethics bodies. The participants heard about good practices in building bioethics networks across state boundaries that bring together national bioethics bodies to tackle issues of common concern and exchange knowledge and experiences. A rich discussion ensued on the need for international organizations to set priorities and coordinate their actions in regards to bioethics networks, (frequency and size of meetings, assistance provided for the participation of representatives from the developing countries, use of the resources for training NBC secretariats from the developing countries, etc.), with an aim to optimize the allocation of scarce resources.

Debating Health and Social Responsibility

The fifth session of the Conference was held as a capacity-building module for the participants who engaged in a thematic debate about the concept of social responsibility and health, and specifically on the role of the bioethics committees in promoting the concept at the national level and influencing public policy.

The participants affirmed the important role of NBCs as catalysts of interaction between the civil society and government on a broad range of public policy issues, including on the responsibility of governments to protect and promote health of citizens. The debate at the Conference echoed the discussion that took place some days earlier at the IBC session around Article 14 on Social Responsibility and Health of the Universal Declaration on Bioethics and Human Rights. Having just finalized the IBC report on this topic, the IBC members presenting at the Conference were able to engage the participants in a lively debate about the role

that their NBC can play in promoting the rights of citizens to basic social and economic standards for healthy living.

According to the Declaration, one of the main functions of the National Bioethics Committees should be to “assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration”. The participants noted that towards this end, the NBCs should be part of the national policy debate on research and development priorities of the country, for them to provide input that reflects bioethical perspectives. This would represent a way of linking the Article on the promotion of health and social responsibility to the need for developing sustainable research policy priorities in the countries concerned. Some representatives of NBCs from developing countries noted the risk of over-extending the scope of the newly established bioethics committees who struggle to define the precise areas of activity.

Conclusions and Follow-up

The debates revealed that bioethics is increasingly prominent on the political agenda of governments around the world. This creates an atmosphere conducive to awareness-raising on pressing bioethics topics and positive interventions from the national bioethics committees. In the Conference outcome document that summarized the ideas generated during the sessions, the participants reaffirmed the indispensable role that national bioethics committees play in shaping and guiding bioethics discourse and practices at the national level. The participants also requested UNESCO and European Commission to continue their collaboration to bring together existing bioethics networks to foster exchange of knowledge and ideas (the conclusions document is attached as Annex I).

The Conference has a website, www.unesco.org/bioethics, which serves as a clearing house for information derived from the Conference. *The Conference Programme*, as well as the *Abstracts of the Presentations* and other relevant information have been available online in advance of the Conference in English, French and Spanish languages. The web site will soon also contain the *Conference Final Report*, *Conference Conclusions document*, and all the delivered presentations.

As a follow up to the Conference, UNESCO has published a book titled *National Bioethics Committees in Action*, which brings together papers submitted by the participants and based on their presentations. The eighteen papers collected together represent a solid, substantive volume of information regarding the major themes of the Conference, and are available for the participants on the Conference web site.

Coverage of the Conference

In the run-up to the Conference, two announcements were made through UNESCO’s system of ethics databases GEObs (www.unesco.org/shs/ethics/geobs),

which notified the individual experts in ethics, as well as Ethics Institutions, centers, commissions, and committees in the area of ethics around the globe about the Conference. In addition, announcement about the Conference was disseminated through a monthly SHS e-newsletter, which has 13, 600 subscribers in the field of ethics. Moreover, announcements about the conference were made by several national bioethics committees on their websites, such as the one for the National Bioethics Committee of Mexico.

A feature article appeared about the Conference in the spring 2009 issue of the *SHS Views* (N 24) – a quarterly magazine of the Social and Human Sciences Sector of UNESCO (available online at www.unesco.org/shs/views), with a note about its postponement due to the outbreak of the A(H1N1) virus epidemic. The October-December 2009 issue (N 26) of the *SHS Views* magazine announced the new dates of the Conference, and the subsequent issue in February 2010 featured an article summarizing the Conference and the planned follow-up activities (the three articles are attached in Annex II).

Annex I

EUROPEAN COMMISSION-UNESCO CONFERENCE: JOINT ACTION FOR CAPACITY-BUILDING IN BIOETHICS (Mexico City, Mexico, 26-28 November 2009)

Conclusions in order to promote international cooperation for knowledge-sharing and mutual capacity-building among national bioethics committees

The participants in the UNESCO – European Commission Conference: Joint Action for Capacity-Building in Bioethics (JACOB), held on 26 to 28 November 2009 in Mexico City, Mexico,

Noting that in accordance to Article 19 of the Universal Declaration on Bioethics and Human Rights, adopted by acclamation on 19 October 2005 by the 33rd session of the General Conference of UNESCO, independent, multidisciplinary and pluralist ethics committees are indispensable at the appropriate level for shaping and guiding bioethics discourse and practices,

Acknowledging the contribution made by the existing national bioethics bodies to the development of bioethics in their respective countries, and the accumulation of significant experience in shaping related debates and policies,

Considering the growing number of countries having recently established, or being in the process of establishing bioethics committees at the national level, and the expressed need for capacity-building for these committees,

Welcoming the commitment of UNESCO, the European Commission, WHO, and other international and regional organizations to provide assistance to countries in establishing and developing their national bioethics infrastructures for meaningful and effective engagement in ethics-related policy issues,

Recognizing the mutual benefits for the national bioethics committees in sharing the experiences and knowledge, especially for the recently established and planned committees,

Acknowledging the proliferation and strengthening of regional bioethics networks, such as the Latin American and Caribbean Bioethics Network (Redbioética), the Forum of National Ethics Councils of the European Commission (NEC Forum), as well as the West African Bioethics Forum and other regional networks being currently in progress,

Emphasizing the value of experience and knowledge exchange at the regional level regarding issues and challenges shared by bioethics committees from the same region,

Aware of the challenges of globalization of biomedical research and healthcare, particularly for developing countries, and the need for appropriate policy responses on the basis of international solidarity and global justice,

Hereby conclude that we find it necessary to:

- Encourage countries to establish independent, multidisciplinary and pluralist bioethics committees at the national level and to empower them for an effective engagement in ethics debates arising from inequalities in the access to health care, new scientific advances, new biotechnologies, and the related government policies and regulations;
- Support bilateral and multilateral initiatives designed to raise the capacity of the newly established committees, including professional exchanges between the secretariats of experienced and newly established committees;
- Use and promote the available resources, such as the databases of the UNESCO Global Ethics Observatory (GEObs), as platforms of exchange of knowledge and information regarding the existing ethics institutions, as well as ethics teaching programmes, ethics related legislation and guidelines, codes of conduct and ethics resources;
- Promote regional bioethics networks that actively facilitate exchange of knowledge and best practices concerning bioethical issues of common concern;
- Explore ways to bring together existing bioethics networks to foster exchange of knowledge and ideas about the emerging bioethics trends and challenges in various regions.
- Invite the European Commission and UNESCO to continue to collaborate to further promote these activities.

April – June 2009

UNESCO Social and Human Sciences Sector magazine

24

SPECIAL SECTION

**1st World Social
Sciences Forum
in Bergen**

INTERVIEW

**Pr. N'galadjo Bamba:
“Development is a
change in attitudes”**

DOSSIER

**Focus on
the Netherlands**



Pandemics and Bioethics

The outbreak of a new virus has led the World Health Organization to raise its pandemic alert to phase 5 on the scale of 6. Since the Mexican Ministry of Health began to notice in late March the symptoms of this entirely new hybrid strain of influenza virus, the international community has demonstrated its amazing resolve to cooperate in order to prevent the spread of the virus and mitigate its impact on people. As a matter of precaution, Mexican authorities have called off public events, and closed all non-essential services including schools and universities.

Due to these developments and in close consultation with the Mexican authorities, we have postponed to a later date two major international events which were to be held in Mexico City in May – the 16th Ordinary Session of International Bioethics Committee and the joint European Commission-UNESCO Conference “Joint action for capacity building in bioethics”. The World Health Organization (WHO) has been working for a number of years on the range of challenging ethical issues raised by a potential influenza pandemic, to provide Member States with practical guidance on how to incorporate ethical and related human rights and legal considerations into their plans and preparation for, and response to, pandemic influenza. For instance, the WHO Guidelines for investigation of human cases of avian influenza A (H5N1) were published in January 2007.

This current health situation clearly shows that no nation is immune to the growing global threat posed by an isolated outbreak of infectious disease in a single part of the world. As people, goods and food travel the world in unprecedented numbers and at historic speeds, so too do the myriad of disease-causing microorganisms. Because national borders offer trivial impediment to such threats, one nation’s problem soon becomes a problem shared by all nations. The emergence of epidemics/pandemics therefore emphasizes the importance of thinking globally about health, particularly from an ethical point of view.

The Universal Declaration on Bioethics and Human Rights, adopted by the UNESCO’s General Conference in 2005, whilst affirming widely accepted bioethical principles such as respect for individual autonomy and consent, also broadens the bioethics perspective emphasizing the need of a communitarian and global approach to urgent issues for many countries. ¶



Pierre Sané
Assistant Director-General
of UNESCO for Social
and Human Sciences

Ethics of Science

Toward an international network of National Bioethics Committees 3
Report of the 16th session of the International Bioethics Committee 4
Development of nanotechnologies: A key debate in the Arab States ... 5
In Monaco, experts at the Arctic’s bedside..... 6

Social Transformations

Regional integration: a future research institute in Cape Verde..... 7

Professor Lambert N’galadjo Bamba: “Development is a change in attitudes” 8

Special Section: 1st World Social Sciences Forum 10-15

UNESCO manages a project for Youth with 21 organizations 16

Human Rights

Advocating for social justice and human rights in London 17
The financial crisis and gender issues: A study carried out on five continents 18
Poverty and human rights: Creation of a UNESCO Chair at the University of Bologna 19
Small grants for research in Sub-Saharan Africa..... 19
Racism: What challenges for UNESCO? 19
Cities against racism: extending ECCAR to Eastern Europe 19

Dossier



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Focus on Netherlands 22-28
Social and Human Sciences within National Commissions for UNESCO

Reader’s forum 29
Publications 30
Calendar 32



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COOPERATION

Towards an international network of National Bioethics Committees

Postponed due to the health situation in Mexico, a conference which should have taken place in Mexico City from 7-9 May 2009 would have led to the creation of a global network of National Bioethics Committees. Such a network would have facilitated the mutual strengthening of current structures and enhanced North-South and South-South cooperation.

If the situation were not so tragic, it would be a painful irony of fate. The terrible epidemic of swine flu appeared in Mexico at a time when Mexico City was preparing to be the setting of a historic milestone for international cooperation in bioethics.

It was in this city that the dynamic Latin-American network “Redbioética” was created in May 2003. The city should therefore have been capable of linking together the National Bioethics Committees around the world, through a conference organized by UNESCO and the European Commission that was to have been held during the 16th Session of the International Bioethics Committee (see next page).

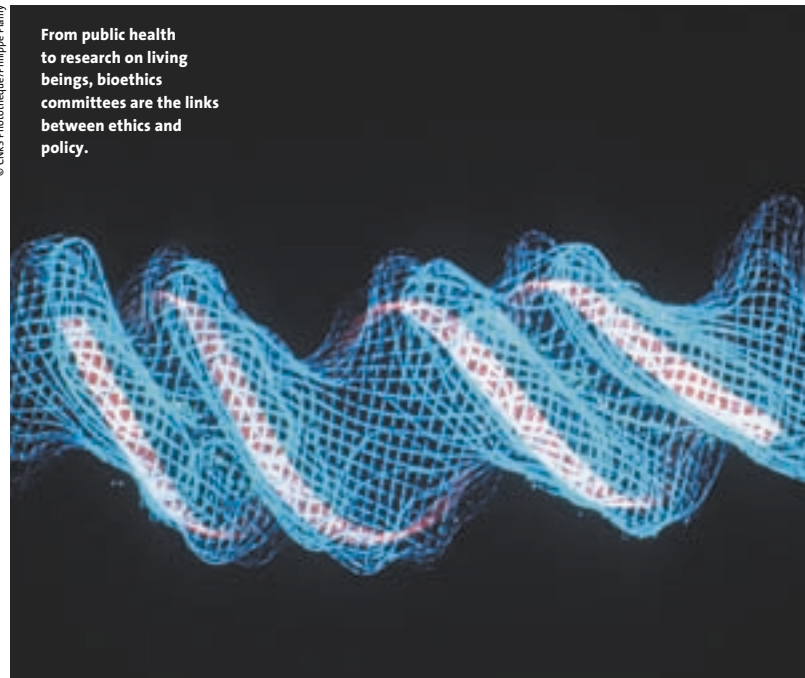
Just like the meeting of the IBC, the conference – called the “Jacob Conference” – has been postponed. It was initially intended to bring together, in the Mexican capital, experts and members of National Bioethics Committees from Africa, Latin America and the Caribbean, Asia and the Pacific, the Arab States and Europe from 7-9 May 2009, with the objective of strengthening national infrastructures in the field of bioethics by promoting the development of independent, multi-disciplinary and pluralist ethics committees.

A common vision

Three themes were on the agenda: emerging issues in bioethics; engagement in an ethics discourse; and the establishment of an international network. This latter theme should have been a major event. The creation of such a network would have added a new dimension to efforts undertaken by UNESCO Member States in the areas of bioethics and human rights.

By establishing a collaborative framework between National Bioethics Committees at a global scale, this network could have strengthened the capacities of all concerned and significantly increased North-South and South-South cooperation. To do this, a common vision for mutual enrichment should have first been identified. This was to be one of the objectives of the conference in Mexico City, which would have given participants not only the opportunity to share their knowledge and experience in the management of these Committees, but also to share their views on how they could have effectively participated in decision-making, contributed to the establishment of priorities and advised on policy.

National Bioethics Committees are expected to play an important role in the development of a bioethics discourse and have an impact on laws, regulations and practices..



From public health to research on living beings, bioethics committees are the links between ethics and policy.

Bioethics touches on a number of pertinent issues from public health and medical care to research on living beings, social and environmental adaptation, or even conservation of natural resources. None of these issues can be effectively addressed from a purely academic perspective. These

issues have direct policy implications, particularly in areas relating to poverty, inequality and social exclusion.

As a linkage between ethics and politics, National Bioethics Committees are expected to play an important role in the development of a bioethics discourse and have an impact on laws, regulations and practices at the local level.

The conference in Mexico City should have provided participants with an invaluable opportunity to discuss their needs, the challenges they face and the experiences they have gained. Using specific examples, participants would have been invited to discuss issues common to different regions of the world and the institutional mechanisms established at the national level to respond to these

issues. For the first time, participants planned to adopt a Declaration to establish an international network which would give them even more strength and visibility. UNESCO hopes that the meeting can take place in Mexico City in the coming months. ¶

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COMEST

Climate change: Moving towards a universal ethical framework?

Among the recommendations forwarded to the Director-General of UNESCO at the end of the 6th session of the World Commission on Scientific Knowledge and Technology (COMEST), held from 16 to 19 June 2009 in Kuala Lumpur (Malaysia), is the development of an ethical framework of principles in relation to climate change by the Organization. According to the 18 independent experts of COMEST, there is an urgent need to establish universal ethical principles that can guide the responses to challenges.

These principles include: the right to share in scientific advancement and its benefits, the precautionary principle; the principle of shared but differentiated responsibilities; the principle of sustainability; the principle of integrity as applied to ecosystems; and the principle of safeguarding and promoting the interests of future generations. In addition to the agreement and the formulation of

principles currently approved, all this could, according to COMEST, provide the international community with a powerful tool to formulate comprehensive and ambitious responses to the challenges of climate change at all levels.

Normative instruments already exist

Pending the outcome of discussions, there exists the possibility of relying on several international normative instruments currently in force, including the United Nations Framework Convention on Climate Change, the Kyoto Protocol, the Convention on Biological Diversity, and the Declaration on the Responsibilities of Present Generations towards Future Generations, adopted by UNESCO in 1997. ¶

The recommendations of the 6th Session of COMEST are available at <http://unesdoc.unesco.org/images/0018/001831/18314oe.pdf>

ETHICS EDUCATION

Creating a national network of bioethics in Bangladesh

Bioethics education should soon move forward significantly in Bangladesh, thanks to the creation of the Bangladesh Bioethics Association (BBA) which was launched at a 2nd workshop organized by UNESCO from 11 to 12 July 2009 in Dhaka. The Executive Committee and the Advisory Committee of the association, elected on this occasion, are responsible for encouraging the granting of scholarships to students, and ensuring that the principles contained in the Universal Declaration on Bioethics and Human Rights, adopted by UNESCO in 2005, are observed.

Is a Bioethics Committee forthcoming?

At the opening session of the workshop organized by the Regional Unit for Social and Human Sciences in Asia-Pacific (RUSHSAP) of the UNESCO office in Bangkok in close cooperation with the UNESCO Office in Dhaka and Bangladesh Academy of Social Sciences, the Chairperson of the University Grants Commission

of Bangladesh expressed the urgent need to establish ethics courses in different universities across the country which is facing significant challenges in its struggle for development.

Paying tribute to the creation of this association, Nurul Islam Nahid, Minister of Education of Bangladesh, gave it his full support, and encouraged every individual to continue its work already started for the creation of a National Bioethics Committee, along the same lines as those already established in many countries, under the leadership of UNESCO.

Bringing together 70 people from diverse backgrounds, this important workshop drew on the results of working groups set up at the 1st workshop on ethics, held on 17 and 18 March 2009 in Dhaka (See *SHSviews* n°25, page 6). ¶

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El Salvador establishes its National Bioethics Committee

By ministerial decree, a National Bioethics Commission was established in El Salvador in May 2009 with a mandate to participate in the development of legal and policy frameworks to promote the protection and respect of life, the environment and human dignity. ¶

For more information, please contact: Gisselle Burbano Fuentes ag.burbano-fuentes@unesco.org tel.: +33 1 45 68 44 33

Debate in Japan on "What is medical"?

The island of Kyushu (Japan) will house on 12 and 13 December 2009, the 3rd Round Table on Bioethics to be organized by the University of Kumamoto and UNESCO Bangkok office. Discussions will focus on what is medical or not: this debate is all the more necessary today since these boundaries, which vary from one culture to another, are of great importance for the development of ethical policies to implement international standards on ethics. ¶

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Bioethics: the European Commission and UNESCO form an alliance

In collaboration with the European Commission, UNESCO is organizing a conference to strengthen the infrastructure of its Member States in bioethics from 26 to 28 November 2009, in Mexico City (Mexico). This meeting will bring together experts and members of National Bioethics Committees from around the world, whether newly created, in the process of or already established. ¶

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January 2010-March 2010

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27



CLIMATE CHANGE

**Patricio Bernal
on the Copenhagen
Summit**

HUMAN RIGHTS

**Arab-African
migration:
talking frankly
in Cairo**

5TH WORLD URBAN FORUM

**Meeting in Rio
for cities with
a human face**

This issue of *SHSviews* is accompanied by a special issue presenting the strategy of UNESCO's Social and Human Sciences programme for 2010-2011 and looks back over the main results obtained during the past decade.

IN THE TABLE OF CONTENTS:

- 2 / **UNESCO's social and human sciences strategy for 2010-2011**
- 3 / **Three questions for... Pierre Sané**
- 5 / **The ethical challenges of climate change**
- 8 / **The Youth Challenge**
- 9 / **Strengthening the social research-policy nexus**
- 10 / **Promoting human rights and empowering women**
- 12 / **SHS: 10 years of action in pictures**

CENTRAL POSTER /

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CONTENTS
JANUARY–MARCH 2010

**Ethics
of Science**

Bioethics Committees networked in Mexico 3
The IBC will continue research on human cloning 4
A question for... Patricio Bernal 5

Human Rights

Arab-African migration: talking frankly in Cairo 6
Somalia: the "Greater Horn Horizon" offers prospects for ending the crisis 8
Poverty and human rights: decision-making tools 9
Two humanists share the 2009 Madanjeet Singh Prize 10
Gala for the Education of Children in Need 11
World Philosophy Day 2009: several thousand participants in 35 countries 12
First Assembly of the International Network of Women Philosophers 13
Advocacy in Indonesia for more inclusive societies 14

**Social
Transformations**

Meeting in Rio for cities with a human face 15
An international exhibition on "Better City, Better Life" 16
Increase in Funds to Fight against Doping 17
Social development: a regional framework for East Africa 18

Publications 19
Calendar 20

Last minute
Preview of *Invictus* at UNESCO Headquarters 20
Towards worldwide monitoring of youth initiatives 20
The World Youth Conference in Mexico City 20



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THE JACOB CONFERENCE

Bioethics Committees networked in Mexico

Jointly organizing for the first time together a conference on National Infrastructures for Bioethics, UNESCO and the European Commission facilitated the sharing of experiences to help boost North-South and South-South cooperation in this field.

Organized by UNESCO and the European Commission, a conference called “The JACOB Conference” gathered together in Mexico City (Mexico) from 26 to 28 November 2009, over 100 participants from national bioethics bodies and international and regional organizations working in this area, to ensure the sharing of knowledge and experiences on this issue. A perfectly legitimate ambition for UNESCO, which derives its mandate from the Universal Declaration on Bioethics and Human Rights, which states that “independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level” (Article 19).

Functioning of the committees

Indeed, the conference provided a unique opportunity for experts from newly-established committees to share their experiences of the challenges they face. The meeting also welcomed speakers from countries about to establish a national committee, and representatives of national committees already established.

Presentations and debates revealed a number of interesting issues that all bioethics committees should consider. Can a committee which is financially supported by a governmental body, such as a ministry, be truly independent and free from any undue influence exercised by the government? Should all voices be heard during the proceedings, even those challenging the principles of fundamental human rights underlying bioethics?

Diversity of opinion

Most participants recognized that it was essential that the argument made by the Committee be inspired by the diversity of opinion and this regardless of the funding source, the independence acquired by the daily activities of the committee, the quality of its work, and the personal integrity of its members.

The discussions showed that bioethics is increasingly present on the political agenda of governments around the world, creating an atmosphere conducive to increased awareness and positive interventions of National Bioethics Committees.

UNESCO was requested to continue, in collaboration with other key organizations working to promote global bioethics, assisting its Member States to build and support the development of national infrastructures for Bioethics and share information through networks of bioethics’ networks. ¶

For more information, please contact:
www.unesco.org/ethics/abc

21

The number of countries involved in the activities developed by UNESCO as part of its Assisting Bioethics Committees project (ABC). (UNESCO, 2010)