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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 will publish a compilation of papers, submitted by the participants and based on their presentations. The fifteen papers collected together represent a solid, substantive volume of information regarding the major themes of the Conference, and will also be made available for the participants on the Conference web site.

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.