

Reflecting on the Past, Present, and
Future Impact of National Bioethics
Advisory Bodies:
***International Capacity Building
Initiatives***

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Structure of the presentation

I. UNESCO and international capacity building of national ethics committees (NECs)

II. Two levels of capacity building

Establishing/training of new NECs – ABC project

Facilitating the activities of existing NECs:

General IBC/IGBC/COMEST activities

Other initiatives – *Global Summit*

III. Challenges to NECs

International bodies for capacity building of NECs

- ***European initiatives***
 - *NEC Forum* sponsored by the European Commission, which meets on a yearly basis – 28 MS of the EU
 - *European Conference of National Ethics Committees (COMETH)* sponsored by the Council of Europe
- ***UNESCO is involved in:***
 - *Global Summit of National Bioethics Advisory Bodies*, meeting on a biannual basis supported by a secretariat at the World Health Organisation
 - *Assisting Bioethics Committees (ABC) Project*

UNESCO Universal Declaration on Bioethics and Human Rights, Article 19

- **“Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:**
 - Assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;
 - Provide advice on ethical problems in clinical settings;
 - **Assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;**
 - **Foster debate, education and public awareness of, and engagement in bioethics.”**

UNESCO Assisting Bioethics Committees (ABC) Project

- Directly follows from the Universal Declaration on Bioethics and Human Rights
- In the majority of member states NECs do not exist

Three phases of the ABC project :

- 1. Exploration and assessment of the existing bioethics infrastructure in Member States;
- 2. Technical support for the establishment of the national bioethics committee;
- 3. Technical support for long-term sustainability:
 - a. Technical capacity-building trainings (3 trainings in 3 years);
 - b. Partnerships, internships and networking;
 - c. Provision of practical information.

Committees established in the following Member States

- According to <http://unesdoc.unesco.org/images/0015/001528/152825e.pdf>
- Colombia (2009), Côte d'Ivoire (2002), El Salvador (2009), Gabon (2008),
- Ghana (2009), Guinea (2007), Jamaica (2009), Kenya (2008),
- Madagascar (2007), Mali (2009), Oman (2009), Togo (2007)

- *However, no further information about the activities is provided*

Intergovernmental Bioethics Committee (IGBC)



Created in 1998, under Article 11 of the Statutes of the International Bioethics Committee (IBC).

Comprised of 36 Member States whose representatives meet at least once every two years to examine the advice and recommendations of the IBC.

The International Bioethics Committee (IBC)

- **36 independent experts that follow progress in the life sciences and its applications** in order to ensure respect for human dignity and freedom, created in 1993.
- **Main tasks:**
 - reflection
 - exchange of ideas and information
 - heightening awareness
 - co-operation with the international governmental and non-governmental organizations
 - dissemination of the principles set out in the UNESCO Declarations

Topics

Reports of the IBC:

- [The Principle of the Sharing of Benefits](#) (2015)
- [Updating Its Reflection on the Human Genome and Human Rights](#) (2015)
- [The Principle of Non-Discrimination and Non-Stigmatization](#) (2014)
- [Traditional Medicine Systems and their Ethical Implications](#) (2013)
- [The Principle of Respect for Human Vulnerability and Personal Integrity](#) (2013)
- [Report of the IBC on social responsibility and health](#) (2010)
- [Report of IBC on Human Cloning and International Governance](#) (2009)
- [Report of IBC on Consent](#) (2008)

Preliminary Work Programme for 2016-2017

- big data in health care and health research
- bioethical questions arising from conditions of refugees and migrants, with a specific focus on health care

NECs in Europe

- Main functions are very similar all over Europe
 - Opinions/recommendations on bioethical issues
 - Facilitation of public debate
 - Participation in the legislative actions
- However, review of human research projects is a rather common function of NECs in the New Member States of the EU (members from 2004):
 - Most of the biomedical research - Slovenia
 - Multicenter studies – Lithuania
 - Specific projects – e.g., human genome in Latvia
 - Appeal body – Poland

Challenges to NECs: developed countries



Ethics assessment and guidance in different types of organisations

National Ethics Committees

Author: Doris Wolfslehner, Secretariat of the Austrian Bioethics Commission

- **Misinterpretation of NECs activities**
 - › difficult to measure impact
 - › recommendations cannot be directly implemented
 - › cannot offer definitive solutions to problems

Future challenges

- › improving NECs ways and possibilities to reach out to the public
- › addressing new developments regarding emerging technologies

Challenges to NECs: developing countries I

- The main remaining challenge is how to overcome the “asymmetry” between developing and developed countries in terms of:
 - Availability of information on structure/functioning/output
 - Limited resources
 - Difficulties to engage in a pluralistic discourse in the authoritarian/undemocratic societies

Challenges to NECs: developing countries II

- Issues to be prioritized and understanding of what is an “ethical issue” are context specific:
 - E.g., in many developing countries the problem of corruption rather than ethical issues of emerging technologies can be seen as a priority issue
- Controversies of global approaches:
 - Developed countries are less interested in a general framework of principles, while developing countries usually lack resources/means to implement them

Concluding remarks

- Global capacity building initiatives should be more explicit about different challenges faced by the NECs operating in different socio-cultural contexts
- Experience of establishing/building NECs in the EU/Council of Europe member states can be used to better understand processes in the developing countries