



United Nations
Educational, Scientific and
Cultural Organization

SHS/EST/ABC/03/REV.2
July 2010

ASSISTING BIOETHICS COMMITTEES (ABC) PROJECT

MAIN OBJECTIVE: To reinforce bioethics infrastructure in Member States through facilitating the establishment of national bioethics committees, and, once established, through the enhancement of their technical capacities.

I. Introduction

The need to reflect on the ethical dimension of advances in science and technology, as well as the desire to promote informed and transparent public policies that can enhance the public's health has led to the establishment of various forms of Bioethics Committees in many parts of the world. To name just a few, the French *Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé* (CCNE), the National Bioethics Committee in Indonesia and the President's Council on Bioethics in the United States of America serve as platforms for providing guidance and advice to policy makers and governments in their States at the national level. Yet, in the majority of countries, especially in the developing world, such committees do not exist. The ABC project of UNESCO's Bioethics Programme is designed to respond to this need through offering technical guidance and capacity-building to UNESCO Member States interested in building national bioethics infrastructure.

Providing technical assistance in the process of establishment of National Bioethics Committees (NBCs), as well as the subsequent capacity-building for ensuring their viability and sustainability, are essential elements of UNESCO's *capacity-building action* in the field of bioethics. Such committees can be effective platforms from which to implement UNESCO's Declarations in bioethics – the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003) and the Universal Declaration on Bioethics and Human Rights (2005).

While many countries have accumulated experience with research ethics committees that deal specifically with reviewing research protocols, either at the level of hospitals and

research institutes, or at regional or national level, the scope of the ABC project is wider: it focuses on National Bioethics Committees involved in policy-advice, public debate and education at the national level. Therefore, the ABC project *does not* include:

1. Bioethics committees that do not operate at national level, but rather at regional or local levels.
2. National bioethics committees with a narrow mandate. For example, ethics committees working exclusively in the field of research ethics, even if their title is “National Bioethics Committee.”

II. Description

The initial stage of the project envisages exploration and assessment of the existing national bioethics infrastructures, which leads to the identification of countries where UNESCO can provide effective capacity-building assistance based on the interest expressed by the authorities and the real need for a well-functioning national bioethics committee. The project provides a multifaceted and systematic capacity-building assistance containing the following elements: (1) an exploratory mission to assess the state of the art of bioethics infrastructure in the country and to discuss optimal modalities of a committee with the key national stakeholders; (2) technical guidance in the establishment of a national bioethics committee; (3) a Memorandum of Understanding between UNESCO and the newly established committee stipulating three year-long capacity-building assistance; (4) provision of documentation; and (5) facilitation of internships, partnerships, and other networking opportunities.

The experience, expertise and resources accumulated by long-standing national bioethics committees in many countries represent valuable resources that can be transferred to countries planning to establish national bioethics infrastructure. At the same time, the establishment and operation of bioethics committees should also be tailored to individual country needs, taking into account its culture, history and traditions.

The project involves three groups of expert trainers – English, French and Spanish speaking - who have practical experience in national bioethics committees of their countries (see Annex 1). During preparatory meetings in Paris in November and December 2006, these experts have developed a common methodology and a plan of action. The expert groups provide key technical support to the newly established committees during the three phases of capacity building.

III. Three Stages of Capacity-Building

ABC project consist of three phases:

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.

1. Exploratory phase

The first step in the project is to obtain accurate information concerning the state of the art of ethics committees in various Member States of UNESCO. Conducting a “diagnosis” of the ethics infrastructure is necessary so that data can be gathered concerning available ethics expertise, ethics education at university level, ethics advisory bodies at different levels, ethics related legislation and guidelines, codes of conduct, ethics review mechanisms, etc. This information is also used for UNESCO’s Global Ethics Observatory (GEObs) – a system of databases with worldwide coverage in bioethics, which is an important tool for gathering and using information on national ethics infrastructure of countries.

2. Technical support for the establishment of the Committee

In order to provide expert guidance to the national stakeholders engaged in the process of setting up a national bioethics committee, a technical exploratory mission is undertaken to the concerned Member States. With the support of the National Commission for UNESCO, all interested parties are invited to a preparatory meeting to discuss the needs of the country, the optimal modalities of a committee and the practical steps to be taken towards its establishment.

Once a National Bioethics Committee is established, its inauguration is organized alongside a rotating conference or other bioethics awareness-raising event that involves multiple stakeholders and targets general public. This inaugural event also serves as an occasion to formally sign the Memorandum of Understanding with UNESCO as the beginning of the 3 year period of technical support.

3. Technical Support for long-term sustainability

a. Technical capacity-building trainings (3 trainings in 3 years)

First Year

As specified in the Memorandum of Understanding (MOU) agreed between UNESCO and the National Bioethics Committee, which takes into account the needs and wishes of the partners, a wide range of technical support activities can be organized, including:

- First training for the newly established NBCs: Working Methods (see Annex 2)
- Building up relevant documentation (see Annex 4)
- Training of the Committee’s secretariat (see Annex 6)

UNESCO Guide N°1 (Establishing Bioethics Committees) and Guide N°2 (Bioethics Committees at Work: Procedures and Policies) are used during the training.

Second Year

- Second training in ethics: Bioethics – Principles and Practices. The course will be based on UNESCO’s Core Curriculum in Bioethics, which is itself based on the principles enshrined in the Universal Declaration on Bioethics and Human Rights (see Annex 3);
- Public event to disseminate the work of the committee. This event can take the form of a rotating conference and can be used as an opportunity to disseminate information about UNESCO’s ethics programme.

Third Year

- The major focus during the third year will be on ensuring the long-term sustainability and viability of the newly established NBC, and will involve specialized training in ethics (ethics education, legal provisions, etc), targeting the issues identified as a priority by the Committee.

b. Partnerships, Internships and Networking

In addition to trainings, the ABC project offers capacity-building to the newly established committees through (1) internships for the secretariat members hosted by experienced committees, (2) partnerships with the experienced committees for a long-term, sustained guidance, and (3) networking opportunities at regional and international levels.

ABC project facilitates the establishment of long-term partnerships between the experienced and newly established national bioethics committees, for sustained exchange of knowledge, experience and resources (see Annex 5).

Experience from long-standing National Bioethics Committees has made it clear that a well-functioning secretariat is of crucial importance for the sustainability of a committee. For this reason, ABC project facilitates internship arrangement where the secretariat of an experienced committee hosts a secretary of newly established NBC to observe and learn the logistics, working methods and procedures of a committee secretariat (see Annex 6).

Moreover, ABC project supports the creation of regional bioethics networks that enable NBCs from the same region to share lessons learned and best practices on issues of common concern (see Annex 7). The establishment of Western and Central African Bioethics Forum, the network of NBCs from CIS region, and other regional networks is currently in progress.

4. Provision of Practical Information

Practical information about the national bioethics committees have been assembled in a series of UNESCO guides:

Guide N°1: Establishing Bioethics Committees

This guide provides information regarding the differences between committees of various types (policy-making/advisory, health-professional association, hospital, research ethics) and levels (national, regional, local), as well as practical information on the steps to be taken when creating a National Bioethics Committee.

Guide N°2: Bioethics Committees at Work: Procedures and Policies

The guide provides practical information concerning general (preparing for meetings, recording of meetings, etc.) and specific procedures for each form of committee. It also explains how committees can be evaluated in order to improve their performance. Finally, it points to ways to enhance and expand the influence of the committee.

Guide N°3: Educating Bioethics Committees

This guide offers to its users various topics for ethics education, as well as examples of the existing training programs in different countries. A list of international journals on bioethics, as well as an overview of web-based resources useful for ethics education is also provided in this guide.

Two additional guides are currently under preparation:

Guide N°4: Bioethics Committees and Policymaking; and

Guide N°5: Bioethics Committees and Public Debate

In addition to these publications, UNESCO, in partnership with other ethics institutions, such as the Kennedy Institute of Ethics of Georgetown University (USA) and the Bioethics Commission of Quebec (Canada) provides ethics publications on a wide range of topics to the newly established NBCs (see Annex 4).

IV. Present State of the ABC Project

Committees have already been established in the following Member States:

- 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)

Discussions are ongoing regarding the establishment of an NBC with the following Member States:

- Botswana
- Cap-Verde
- Chad
- China
- Comoros
- Malaysia
- Malawi
- Mauritius
- Namibia
- Niger
- Nigeria
- Trinidad and Tobago

Committees that have signed a Memorandum of Understanding with UNESCO:

- Côte d'Ivoire (first training held in December 2009)
- Gabon (first training held in June 2009)
- Ghana (first training held in January 2009)
- Guinea (first training held in April 2009)
- Jamaica (first training held in March 2009)
- Kenya (first training held in November 2009)
- Togo (first training held in January 2009)

The second training for these committees is planned during the biennium 2010-2011:

Cote d'Ivoire (Sep. 2010)
Gabon (Sep. 2010)
Ghana (Fall 2010)
Guinea (Dec 2010)
Jamaica (Nov. 2010)
Kenya (Nov. 2010)
Madagascar (Fall 2010)
Togo (Oct. 2010)

Further Information

For more information concerning the ABC project, please contact:

Ms. Dafna Feinholz
Chief of Section
Bioethics Section
Division of Ethics of Science and Technology
Sector for Social and Human Sciences
Email: d.feinholz@unesco.org
Tel: +33 (0) 1 45 68 49 94

Mr. Irakli Khodeli
Assistant Programme Specialist
Bioethics Section
Division of Ethics of Science and Technology
Sector for Social and Human Sciences
Email: i.khodeli@unesco.org
Tel: +33 (0) 1 45 68 44 33

ANNEX 1: EXPERTS PARTICIPATING IN ABC PROJECT

Vasantha Muthuswamy

Indian Council of Medical Research Ansari Nagar
Senior Deputy Director General & Chief
Division of Basic Medical Sciences, Traditional Medicine & Bioethics
Email: muthuswamyv@icmr.org.in

Marie-Helene Mouneyrat

Secrtaire General du CCNE
Comite Consultatif National d’Ethique
7, rue Saint Georges
75009 Paris,
France
Email: mialet@comite-ethique.fr

Abdulaziz Al-Swailem

National Resources and Environment Research Institute, Director
Biotechnology Research Center, Chairman
National Committee of Bio- and Medical Ethics, Chairman
King Abdulaziz City for Science and Technology
Riyadh 11442
P.O. 6086
Kingdom of Saudi Arabia
Email: alswailem@kacst.edu.sa

Harald Schmidt

Assistant Director
Nuffield Council on Bioethics
28 Bedford Square
London WC1B 3JS
United Kingdom
Email: hschmidt@nuffieldbioethics.org

Evariste Likinda

Chair National Bioethics Committee
Democratic Republic of Congo
Email: evalik2@hotmail.com

Hans van Delden

University Medical Center Utrecht
Heidelberglaan 100
3584 CX Utrecht
The Netherlands
j.j.m.vandelden@umcutrecht.nl
h.meegdes@umcutrecht.nl

Jan Helge Solbakk

Former Director of the Norwegian National Medical Research Ethics Committee
Professor of Medical Ethics

Section for Medical Ethics
Institute of General Practice and Community Medicine
Faculty of Medicine, University of Oslo
Box 1130 Blindern
N-0318 Oslo
Email: j.h.solbakk@medisin.uio.no

Jean Martín

Privat-Dozent à l'Université de Lausanne
Membre de la Commission nationale suisse d'éthique
La Ruelle 6
CH-1026 Echandens
Suisse
Tel & Fax: (41) 21 701 09 84
E-mail: jean.martin@urbanet.ch

Marie-Geneviève Pinsart

Free University of Brussels, Belgium
Co-Director of the Interdisciplinary Research Centre
Avenue F. Roosevelt, 50
CP 175
1050 Brussels
Belgium
Phone: +32 2 650-2343
Fax: +32 2 650-3647
Email: gpinsart@ulb.ac.be

Christian Hervé

Laboratoire d'éthique médicale
Université Paris-Descartes
Faculté de Médecine
45, rue des Saints Peres
75006 Paris
Email: herve@necker.fr
www.ethique.inserm.fr

Christiane Woopen

Institut für Geschichte und Ethik der Medizin
Forschungsstelle Ethik
Uniklinik Köln
Herderstr. 54, 50931 Köln
Tel: 0221 - 478-86990; Fax: 0221 - 478-86996
Email: christiane.woopen@uni-koeln.de
<http://cms.uk-koeln.de/ethik>

ANNEX 2: FIRST TRAINING FOR NEWLY ESTABLISHED NBCs

Working Methods

Introduction

In the framework of the Assisting Bioethics Committees project (ABC) of UNESCO, the Division of Ethics of Science and Technology organizes a series of training sessions for National Bioethics Committees. The first year of the ABC project features a training course on working methods for NBCs, followed by an introduction into bioethics training course in the second year.

Background

This training is the first activity in the ABC project framework after the establishment of a national bioethics committee. While each committee has to develop its working methods and procedures, which will imply further specifications and applications of its mandate as formulated in its terms of reference, practical experiences and best practices of committees that are operational for a much longer time can be shared and discussed, so that the recently established committees can learn from the successes and failures of other committees.

Objectives

- clarify the role and mission of the committee
- develop clear working methods
- draft rules of procedure
- develop policy for record management
- develop policies for public information
- develop policies for networking

Expert teams (please see Annex 1)

- French speaking team
- English speaking team
- Spanish speaking team

Programme

Day 1: Morning – Visions and perspectives

I. Welcome and introduction

Presentation: The ABC project of UNESCO: how to make the committee sustainable?

II. Exercise No 1: The committee (discussion and work in small groups)

III. Reflection on the goals and role of the committee

- What is the mission of the committee? Can a mission statement be formulated?
- What are the opportunities and challenges of the committee?

IV. Presentation: The chairperson

- What is the role of the chairperson?

V. Presentation: The secretariat

- What is the role of the secretary?

Day 1: Afternoon: Working methods

Meetings of the committee

- how is the committee going to deliberate
 - rules of procedure
 - examples: International Bioethics Committee
 - decisions by consensus or voting
- policy for agenda setting
 - what kind of issues will be discussed
 - who is authorized to bring such issues
 - how are they prepared
- open meetings
 - criteria for presence of non-members
 - criteria for participation of non-members
- publication of decisions
- provide written justifications of decisions

Day 2: Morning: Working methods - continued

Exercise No. 2: Rules of procedure (work in small groups)

- draft rules of procedure
- discussion of drafts

Day 2: Afternoon – Operational procedures

I. Where and how to get information for the committee

II. Records of meetings

- custody of records and documentation
- who has access to the records
- under what circumstances
- how is confidentiality and privacy of members guaranteed
- how long are records retained in the files

III. Financial support and annual budget

Day 3: morning – Effective membership

I. What is the role of members?

II. Procedures for recruitment of committee members

- Who has selected and appointed committee members
- criteria for membership

- are members representing various constituencies
 - what does representation mean?
 - how are we going to do that?
- what is the range of specialties and expertise in the committee
- can members be removed

III. Education of members

Day 3: afternoon – Outreach of the committee

I. Relationship to the media

- how will the public and the media be informed
- public events

II. Relationship with other bodies

- other ethics committees in the country
- bioethics committees in other countries
- academic institutions
- governmental bodies

III. Independency of the committee

IV. Summary and conclusion

ANNEX 3: SECOND TRAINING FOR NEWLY ESTABLISHED NBCs

Bioethics: Principles and Practices

Introduction

In the second year of the ABC Project, an introduction in bioethics is offered as a training course for members of the recently established national bioethics committees. This training will be based on the principles of the *Universal Declaration on Bioethics and Human Rights* that has been agreed upon unanimously by all Member States of UNESCO in 2005.

Objectives

The training will provide an introduction into the fundamental principles of bioethics and their application in various circumstances and practices. The general objectives of the training are:

1. the participants should be able to identify ethical issues in problems addressed by national bioethics committees,
2. the participants should be able to provide rational justification for ethical analysis, advice and recommendations,
3. the participants should be able to apply the ethical principles of the *Universal Declaration on Bioethics and Human Rights*, thus strengthening the basis and relevance of the work of the newly established committee.

Time frame and organization

Each training session will last one workweek of five days. The training will be provided by three experts from the UNESCO ABC task force. It will take place in the framework of the Memorandum of Understanding signed between UNESCO and the NBC. The training will be the second activity in the context of this cooperation.

While UNESCO will provide the training and will fund the missions of the experts, participating NBCs will ensure the participation of their members and will assist the UNESCO Secretariat in organizing the missions (airport transfer, hotel reservation).

The first step in the organization of the training will be the determination of a time, so that the week can be blocked for this activity by all members of the National Bioethics Committee as well as the experts involved.

Preparation and assignment

Each participant (member of the NBC) will receive in advance an assignment. He or she will be invited to analyze a specific case using the principles of the *Universal Declaration on Bioethics and Human Rights*. The case can preferably be selected from one's own experience (in research, in health care, in policy making, in governmental work etc.). The most important thing is that it will be a case from real life experience and one which with the participants himself or herself is acquainted and in which he or she has been involved. The case study should be no longer than 800 words in writing. The case should be presented and discussed in maximally 30 minutes during the programme of the training (see schedule).

It is important that each participant will prepare himself or herself by reading through the literature that will be used in the training, so that he or she will benefit maximally from the teaching during the training.

National Bioethics Committees are also invited to submit case studies, examples, questions, issues that have emerged during their recent activities at local, national or regional level. The National Commission for UNESCO will be invited to make certificates to the participants, confirming their participation in the training.

Programme

Day 1: Morning (9-12 am) – Ethics and Bioethics

9-10 am: What is ethics?

- The moral point of view
- Nature of moral judgments
- An ethical method of reasoning

10-11 am: What is bioethics?

- The birth of bioethics
- Health and disease as values
- Principles of bioethics
- Ethics committees
- Medical professionalism

11-12 am: Case study – Patient cleans the apartment: argument for and against, benefit and harm (Case 3, unit 2) (or a case proposed by the NBC in advance of the training)

Day 1: Afternoon (2-6 pm) – Dignity, human rights, benefit and harm

2-4 pm: Dignity and human rights (Article 3)

- Concepts of dignity in the history of ideas
- Human dignity as an intrinsic value of the human person
- Diverse understandings of human dignity in different cultural and moral traditions and societies
- Entailed obligations
- Applications to health-care

3-4 pm: Benefit and harm (Article 4)

- What is a health benefit?
- What is harm?
- How to evaluate them practically

4-6 pm: Presentation and discussion of cases by four participants

Day 2: Morning (9-12 am) – Autonomy and consent

9-10 am: Autonomy and individual responsibility (Article 5)

- Concepts of autonomy and responsibility
- Decision making in medicine
- Responsibilities of the patient
- Evaluation of the patient's abilities

10-11 am: Case study - Discussion of the blood transfusion case (Unit 5)
(or a case proposed by the NBC in advance of the training)

11-12 am: Consent (Article 6)

- Connection with other principles
- Purpose of the principle
- Consent and autonomy
- Explanation of the principle
- Exceptional circumstances

Day 2: Afternoon (2-6 pm) – Persons without the capacity to consent

2-3 pm: Persons without the capacity to consent (Article 7)

- Criteria for capacity to consent
- Categories of persons without the capacity to consent
- Legal provisions
- Procedures, constructing consent
- Research involving human subjects

3-5 pm: Video – Informed consent in developing countries (30') and discussion (Unit 7)
Role play – How to inform patients/subjects (Unit 6)
(or a case proposed by the NBC in advance of the training)

5-6 pm: Presentation and discussion of cases by two participants

Day 3: Morning (9-12 am) – Protection of the individual

9-10 am: Human vulnerability (Article 8)

- Notion of human vulnerability and its different aspects
- The powers of medicine and its issues
- The dilemmas of vulnerability
- Care ethics
- Notion of personal integrity

10-11 am: Privacy and confidentiality (Article 9)

- Duties of health care providers
- Extent of confidentiality

- Justified breaches of confidentiality
- Special circumstances of research

11-12 am: Case study - Publishing a case (Case 6, Unit 9)
(or a case proposed by the NBC in advance of the training)

Day 3: Afternoon (2-6 pm) – Justice

2-3 pm: Equality, justice and equity (Article 10)

- Definitions: equality, equity, justice
- Different types of justice
- Different concepts of distributive justice
- Application in different health care systems around the world
- Right to health care
- Disparities in health status
- Role of health care professionals

3-4 pm: Non-discrimination and non-stigmatisation (Article 11)

- Grounds of discrimination & positive discrimination
- Legal context and limitations of the principle of non-discrimination and non-stigmatization

4-5 pm: Role play - The courage to change (Unit 11)
(or a case proposed by the NBC in advance of the training)

5-6 pm: Presentation and discussion of cases by two participants

Day 4: Morning (9-12 am) – Cultural diversity

9-10 am: Respect for cultural diversity and pluralism (Article 12)

- Background and explanation
- Limits to the consideration for cultural specificities

10-12 am: Video - The Constant Gardener (2h09)
(or a case proposed by the NBC in advance of the training)

Day 4: Afternoon (2-6 pm) – Solidarity, responsibility and sharing of benefits

2-3 pm: Solidarity and cooperation (Article 13)

- Notion of solidarity
- Threats to solidarity in present-day societies
- Solidarity, autonomy and justice
- International research

- Universal healthcare and insurance

3-4 pm: Social responsibility and health (Article 14)

- Highest attainable standard of health as a fundamental human right
- The impact of living conditions
- Duty and responsibilities of the different stakeholders, including governments
- Health and contemporary challenges to global justice

4-5 pm: Sharing of benefits (Article 15)

- Global sharing of the benefits of science and scientific research
- Models of benefit-sharing agreements
- Capacity building and externally funded research
- Improper inducements to participate in research

5-6 pm: Presentation and discussion of cases by two participants

Day 5: Morning (9-12 am) – Widening the Scope

9-10 am: Future generations (Article 16)

- Scope and limits of future related responsibilities
- Do we have obligations to the possible people?
- How to represent the future in present decision-making?
- Health issues for future generations (e.g. Xenotransplantation, GMOs, long-term effects of medication)
- Precautionary principle

10-11 am: Case study - The commission for future generations (Case 1 Unit 16) or The Nanotechnology report (Unit 16)
(or a case proposed by the NBC in advance of the training)

11-12 am: Protection of the environment (Article 17)

- Bioethics and environmental issues
- Different environmental ethics approaches (human-centered or not)
- Basic principles of environmental ethics
- Notion of sustainability

Day 5: Afternoon (2-6 pm) – National Priorities

2-4 pm: Presentation and discussion of cases by four participants

4-6 pm: Work in small groups to explore national priorities and a possible agenda for the NBC;
Discussion of the possible topics for year 3 training;
Evaluation of the training

ANNEX 4: BUILDING UP RELEVANT DOCUMENTATION

Providing practical information to newly established NBCs is part of the ABC programme. Apart from the UNESCO guides, the newly established NBCs will receive printed and electronic materials on various topics of bioethics from UNESCO's partner institutions.

In cooperation with the National Reference Center for Bioethics Literature, Kennedy Institute of Ethics, Georgetown University, USA, sets of relevant documentation will be provided to newly established NBCs. The package, donated in the International Bioethics Exchange Project (IBEP), can be used to set up the first documentation resource for the new committee. It includes the following materials:

- Bibliography of Bioethics, volumes 10-12,14-33
- CD-ROM edition of all the (US) National Bioethics Advisory Commission reports
- CD-ROM edition of the (UK) Nuffield Council on Bioethics reports
- CD-ROM edition of the Scope Notes series 1-46
- Bioethics Searchers Guide 2007 edition
- International Directory of Bioethics Organizations

These materials have already been provided to:

1. Egerton University Regional Documentation Center in Kenya (11 boxes) – received.
2. Togo National Bioethics Committee (1 box) – in shipment
3. Mauritius, Faculty of Science, University of Mauritius (2 boxes) – in shipment.
4. Nigeria – shipment has been made but there has been no confirmation of receipt.

Sources that have agreed to provide bioethics resources in French language to the recently established committees from Francophone Africa include:

- CCNE of France
- UNESCO National Commission of France
- Quebec, Commission de l'éthique de la science et de la technologie
- Université Paris Descartes, UFR Biomédicale des Saints-Peres
- CEERE (Centre Européen d'Enseignement et de Recherche en Ethique)
- Commission Nationale de Sante Publique et de Bioethics du Grand Orient de France

In May 2010, boxes containing materials from these institutions, as well as some UNESCO publications, have been sent to NBCs in Gabon, Guinea, Togo, Madagascar and Cote d'Ivoire (1 box per committee).

ANNEX 5: PARTNERSHIPS

Recently established national bioethics committees can be fragile in the first phase of their existence. They have to acquire appropriate working methods and create a “corporate spirit” among the membership. They also have to obtain status and authority within the country as the proper body for bioethical reflection and advice. The new committee will therefore benefit from the opportunity to share information and experiences with a more experienced national bioethics committee in another Member State.

Practical possibilities for partnership between a newly established committee and an experienced one include:

- Exchange of documentation (see Annex 4): newly created committees often lack documentation and bioethics literature as well as examples of the work (reports, recommendations, policy statements, publications) of other committees.
- Consultation service: members of experienced committees can help newly established committees to optimize their functioning and assess their needs in terms of IT, personnel, and training; they can also assist in addressing these needs. Site visits of the partner committees to assess the needs of the new committee may be necessary.
- Internships for secretaries (see Annex 6): since a well-functioning secretariat is an essential feature of an effective NBC, ABC project envisages an internship hosted by an experienced bioethics committee for the secretary of the newly established committee, to study the logistics, working methods and procedures of a committee secretariat.
- Support bioethics education for committee members (see annex 6): another training need for the secretaries of newly established committees can be formal bioethics education in a Master programme. Experienced committees can help with fellowships, accommodation, personal coaching, identification of master programmes and fellowships.
- Joint activities: the partner committees may initiate common activities such as conferences or publications.

The Nuffield Council for Bioethics (UK); Commission on Ethics of Science and Technology of Quebec, Canada; the Ethics Committee System in Denmark; the Belgian Advisory Committee on Bioethics; and the Norwegian Biotechnology Advisory Board are amongst the experienced NBCs that have expressed interest in partnering with the newly established committees.

ANNEX 6: TRAINING AND INTERNSHIPS FOR NBC SECRETARIATS

Bioethics Training: European Master in Bioethics

The secretary or other members of the committee can be registered as candidates for the European Master in Bioethics; the program provides Erasmus Mundus fellowship for non-European participants (see: <http://masterbioethics.org>).

Internships Programme

Background

Experience from long-standing National Bioethics Committees has made it clear that a well-functioning secretariat is of crucial importance for the sustainability of a committee. For this reason, UNESCO, within the context of the Assisting Bioethics Committees (ABC) project has started discussions with several experienced ethics committees about the possibility of the secretariats of these committees providing practical stages for secretaries of newly established National Bioethics Committees.

Overarching objective

To study the logistics, working methods and procedures of a committee secretariat

Specific objectives

- To study the infrastructure of a well-functioning secretariat:
 - archives
 - library
 - technical facilities
- To observe the preparations of a committee meeting:
 - preparation of minutes from the previous meeting
 - preparation of a meeting agenda
 - distribution of minutes, meeting agenda and other relevant material to the committee members
 - identification of relevant materials in the bioethics literature
 - the role of ad hoc meetings with the chair of the committee in advance of committee meetings
- To participate as observer in at least one committee meeting:
 - observe ways of deliberating about ethical issues
 - observe ways of coping with disagreement between committee members
 - observe procedures of decision making
 - observe preparations of reports on particular topics
 - observe preparations of recommendations
- To observe the follow-up of committee meetings:
 - preparation of minutes from the meeting
 - follow-up of committee decisions
 - preparation of reports on particular topics
 - preparation of recommendations to researchers, policymakers and other relevant stakeholders
- To observe the planning, preparation, organization and follow-up of events of public debate and awareness raising

Responsibility of host institutions

- Assisting the visitors in finding appropriate accommodation
- Providing appropriate study conditions for the visitors
- Assisting the visitors in fulfilling their objectives

Responsibility of visitors

- Complying with any rules of confidentiality of the host institution
- Providing a study report about the objectives achieved and lessons learnt to be addressed to UNESCO, the host institution and the NBC at which the visitor works

Responsibility of UNESCO

- Provision of extra-budgetary funding for the practical stages (travel, accommodation and meals)
- Assistance provided to host institutions in selecting visitors
- Integration of the practical stages program into the ABC project
- Evaluation of the experience with practical stages after a pilot phase of 3-5 years

Duration of practical stages

6 weeks

ANNEX 7: INTERNATIONAL AND REGIONAL NETWORKING

Another modality for capacity-building is the active exchange of experiences between the existing committees. In this context, the newly established committees are encouraged to become members and actively participate in the existing networks, both regional and international, in order to share experiences and enhance competencies.

Some of the existing initiatives that create international, as well as regional networks include:

The Global Summit of National Bioethics Advisory Bodies

The 7th Global Summit was held in 1-2 September 2008 in Paris, France, and was organized by Comité Consultatif National d'Ethique (CCNE) of France; The next biennial gathering will be held in Singapore, on 26-27 July 2010, in conjunction with the 10th World Congress of Bioethics. For more information on the 8th Global Summit, please contact the local organizing committee: Singapore Bioethics Advisory Committee Email: contactus@bioethics-singapore.org

JACOB Conference

Regional networks can be very effective in enabling NBCs from the same region to share lessons learned and best practices on issues of common concern. A significant step towards promoting NBC networks at the regional level was taken at the European Commission - UNESCO Conference: Joint Action for Capacity-building in Bioethics (JACOB) in Mexico City, Mexico, on 26-28 November 2009, when more than 100 participants representing national bioethics bodies, as well as regional and international organizations working in the field of bioethics, affirmed their commitment to promote regional bioethics networks, and asked UNESCO and its partners for assistance in this regard.

National Bioethics Committees Network of the CIS region

The Congress "Bioethics and Human Rights," held in September 2008 in Kazan, Russian Federation, initiated the creation of Regional Network of National Bioethics Committees of CIS countries.

Western and Central African Bioethics Forum

The establishment of Western and Central African Bioethics Forum is currently in progress.