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**Note from the Editor**

The Ethics and Health Unit is keen to relay information about ethics activities that occur at WHO and elsewhere, on a bi-annual basis, and encourages newsletter submissions from partners.

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## Editorial

Dear Colleagues,

The first issue of the Ethics and Health Unit Newsletter had focused on the activities of this Unit. Much of our work would not be possible without our excellent collaborating partners, such as different technical departments at WHO, the WHO Regional Offices, fellow International Organizations, and the WHO Collaborating Centers for Bioethics. This is why, for this second issue, we decided to give the floor to our partners to present some of their activities.



WHO Headquarters, Geneva

The aim is to illustrate the diversity and complementarities of initiatives taken at global, regional and national levels; the complexities of ethical issues raised in the elaboration and implementation of health policies and research activities. The common objective of these activities is to ensure that ethical analysis is an integral part of public health. We will continue to encourage submissions from collaborators for this newsletter. The focus of the next issue will be on the establishment of a Global Network of WHO Collaborating Centers for Bioethics.

### WHO CC: The University of Toronto Joint Centre for Bioethics

The University of Toronto Joint Centre for Bioethics (JCB) has been a WHO Collaborating Centre in Bioethics since 2002. The JCB is a partnership of 15 health sciences organizations in the Greater Toronto Area and the faculties of the University of Toronto. We function as a network engaged in applied bioethics education and research. We support networks of academics and health care professionals in clinical, organizational and research ethics. The JCB supports the following educational programs:

- A professional Masters of Health Science in Bioethics, with an international component funded by the Fogarty International Centre of the U.S. National Institutes of Health
- An interdisciplinary collaborative program in bioethics research with masters and doctoral streams.

Our current collaboration with WHO relates to research in ethical issues in pandemic planning, ethical issues in the response to drug resistant tuberculosis (for which WHO members have recently attended meetings in Canada) and research ethics.



University of Toronto - Joint Centre for Bioethics

For example, in January 2009, the JCB hosted a day long stakeholder forum bringing together policy makers from various levels of government in Canada, representatives of health care professional associations and their regulatory bodies (medicine, nursing, pharmacy, occupational and physical therapy) and special needs populations (seniors groups, aboriginal populations, persons with

disabilities, homeless populations) together to set a research agenda on ethical issues in pandemic preparedness. Andreas Reis attended on behalf of WHO which is a collaborator in this research project. Full details can be found at [www.canprep.ca](http://www.canprep.ca). The JCB recently received a grant to host a meeting of all the WHO collaborating centres in Bioethics in Santiago de Chile in April 2009. At this meeting a work plan for collaboration amongst the collaborating centres will be developed. In the past the JCB has collaborated with WHO on genomics and global health and priority setting.

## France: Un ambassadeur pour la bioéthique

La France a créé en 2005 une fonction d'ambassadeur chargé des questions de bioéthique, placée auprès de son Ministre des affaires étrangères et européennes. Cette décision est venue du constat que plusieurs institutions internationales avaient alors entrepris d'élaborer des normes dans un domaine touchant directement à la dignité et aux droits de l'homme, thèmes sur lesquels la France estime essentiel d'avoir une diplomatie active. Le Conseil de l'Europe, depuis l'adoption de la convention d'Oviedo sur les droits de l'homme et la biomédecine (en 1997) avait mis en chantier plusieurs protocoles additionnels. L'UNESCO, après les déclarations universelles sur le génome humain et les droits de l'homme (en 1997) et sur les données génétiques humaines (en 2003), avait élaboré une déclaration sur la bioéthique et les droits de l'homme (adoptée en 2005), la Commission Européenne, après avoir créé le Groupe Européen d'Ethique des Sciences et des Nouvelles technologies et adopté plusieurs directives, notamment sur la conduite d'essais cliniques de médicaments (en 2001), travaillait sur la traçabilité des tissus et cellules d'origine humaine (directive adoptée en 2006).

Au delà de ce travail normatif, les aspects scientifiques prometteurs pour le progrès du droit à la santé, les enjeux économiques (en termes de brevets notamment), environnementaux, sociaux et de développement s'interpénètrent avec les questions de valeurs; s'y ajoute un sujet auquel la France est très sensible: veiller à ce que les pays en déve-

loppement ne soient pas tenus à la lisière des débats internationaux et ne deviennent les territoires d'expérimentations qui ne respecteraient pas les principes éthiques dont se réclament les pays riches.

La fonction d'ambassadeur chargé de la bioéthique implique d'être en relation avec l'ensemble des organisations internationales concernées à commencer par l'OMS et l'UNESCO, elle consiste aussi à soutenir des initiatives issues des organismes d'Etat ou de la société civile, qui visent à développer les échanges internationaux dans ce domaine; la consolidation des réseaux déjà existants au sein de la Francophonie, en liaison étroite avec l'organisation internationale éponyme, en est un exemple. Enfin cette mission comporte une dimension nationale, celle d'informer le législateur français sur l'évolution des législations des autres pays dans un contexte international très hétérogène et en constante évolution.

*Michel Doucin, Ambassadeur, chargé de la bioéthique et de la responsabilité sociale des entreprises, Ministère des Affaires Etrangères et Européennes*



Doctor staining tissues sections - WHP pictures

## **WHO: Department of Reproductive Health and Research**

In May 1988, the World Health Assembly endorsed policy guidelines outlined by the Director-General, with particular attention to the role of the UNDP/UNFPA/WHO/ World Bank Special Programme of Research, Development and Research Training in Human Reproduction (HRP), (5) promoting ethical practices in the field of human reproduction research to protect the health and rights of individuals in different social and cultural settings" (Resolution WHA 41.9).

This led to the establishment of the Scientific and Ethical Review Group (SERG) with three main responsibilities. Firstly, SERG reviews and assists in the identification and development of specific ethical guidance for research with regard to current activities in sexual and reproductive health (SRH). Secondly, SERG ensures that all HRP supported proposals follow ethical requirements in full compliance with the Programme ethical guidance in the areas of SRH; a process which is currently being conducted in collaboration with the WHO Ethics Review Committee during a trial period. Thirdly, SERG via the Secretariat takes an active role in fostering and promoting increased aware-



Reproductive and family health in Nigeria

ness and use of ethical principles and practices in research in SRH. SERG members, the HRP Secretariat, and WHO collaborating centres support ethics training workshops and incorporate ethical principles into research capacity building activities in specific areas of interest in SRH. Upon request of either WHO Regional or Country Offices, workshops on research ethics which focus on SRH issues have been organized, supported and facilitated by HRP, and those in Francophone Africa have been conducted in collaboration with the Ethics and Health Unit.

## **WHO Western Pacific Regional Office (WPRO)**

WPRO is planning a Regional Workshop for 12 Member States in June 2009 to disseminate the revised "WHO Guiding Principles on Human Organ Transplantation"; promote the deceased organ donation programme; and discuss tissue banking and xenotransplantation. The meeting will address issues and challenges arising from the high demand for organs, tissues and cell transplantation, which far outstrips the supply. This results in ethical challenges such as increased risk of economic exploitation of low-income people, especially in poorly-regulated national systems, as well as 'transplant tourism' and trade in organs.

Recognising the importance of these issues, and responding to Resolutions WHA 40.13, WHA 42.5, WHA 44.25, WHO developed the Guiding Principles on Human Organ Transplantation in 1991. Since then, these principles have had great influence on professional codes and practices and legislation around the world.

In response to WHA57.18, WHO updated the guiding principles in 2008 through an extensive global consultation. The revised Guiding Principles on Organ Transplantation assist Member States to develop legislation, regulations and services to improve safety, quality, efficacy, ethics and transparency in organ transplantation with the following objectives:

- To promote altruistic organ donation to enhance their availability
- To prevent trade in organs and exploitation of humans
- To improve quality, efficacy and safety of donations and transplantation
- To ensure transparency in clinical practice

The WHO Guiding Principles are committed to the principles of human dignity and solidarity, which condemn the buying and selling of human organs for transplantation, and the exploitation of the poor and vulnerable. They emphasize transparency in the process while maintaining the privacy of the donor and recipient.

## Bioethics at the Council of Europe

### **10<sup>th</sup> anniversary:**

#### **Entry into force of the Convention on Human Rights and Biomedicine**

In addition to the 60<sup>th</sup> anniversary of the Council of Europe (CoE), 2009 will mark the 10<sup>th</sup> anniversary of the entry into force of the Convention on Human Rights and Biomedicine (Oviedo Convention).

A conference focusing on the Oviedo Convention's impact and relevance and the enduring nature of the principles will be organised on 3 November 2009, within the framework of the Slovenian chairmanship of the CoE Committee of Ministers. National or regional events will also be held on the occasion of this 10<sup>th</sup> anniversary.

#### **A new Additional Protocol to the Oviedo Convention opened for signature**

A fourth Additional Protocol to the Oviedo Convention, which concerns Genetic Testing for Health Purposes, was opened for signature on 27 November 2008. The Protocol sets down principles relating inter alia to the quality of genetic services, prior information and consent and genetic counselling. It lays down general rules on the conduct of genetic tests, and, for the first time at international level, deals with the directly accessible genetic tests for which a commercial offer could develop in future. It specifies the conditions in which tests may be carried out on persons not able to consent. Finally, it touches on genetic screening.

Text of the Additional Protocol concerning Genetic Testing for Health Purposes available at:

<http://conventions.coe.int/Treaty/EN/Treaties/Html/TestGen.htm>

#### **Predictivity, genetic testing and insurance: a new legal instrument being prepared**

The CoE's Steering Committee on Bioethics (CDBI) is currently working on predictivity and genetic testing in the field of insurance with in view to elaborate a new legal instrument.

#### **Elaboration of a Guide for research ethics committee members**

The CDBI is elaborating a Guide for research ethics committee members with a view to facilitate the implementation of the principles laid down in the adopted European legal instruments.

#### **Bioethics Educational Tool: everything you need to lead a classroom debate**

The CoE has developed an educational tool aiming at facilitating the initiation of an open debate with young people on bioethical issues raised by: organ donation, medically assisted procreation, genetic testing, cloning and biomedical research.

More information at : <http://book.coe.int/EN/>

*Further information on Council of Europe activities in the field of bioethics at:*

<http://www.coe.int/bioethics>,

*Contact person: Mrs Laurence Lwoff, Head of Bioethics Division*

## The Global Forum of Bioethics in Research

### Impressions of GFBR-9 held at Auckland, Aotearoa (New Zealand)

The Ninth Global Forum for Bioethics in Research (GFBR-9) was held in Auckland from 3-5 December 2008. The conference was preceded by a UNESCO workshop on 'Ethics Education' and a UNAIDS African AIDS Vaccine Programme Satellite session on 'Revisiting Ethical Issues in Preventive HIV Vaccine trials in the light of the early closure of the STEP and Phambili trials'.

The conference theme was focused on 'Ethics of Research Involving Indigenous People and Vulnerable populations' and brought participants from across the world to the meeting. It was one of the first forums with a substantial representation from the Pacific region. With a substantial input of delegates from indigenous backgrounds and working with vulnerable populations, and the conference imbibing traditional customs, the forum helped raise awareness of working sensitively and in culturally respectful ways while conducting research. The use of case studies and parallel sessions to allow for discussions in various tracks helped explore issues in detail- these were then brought back as key messages to plenary sessions which

has now been documented as a conference report available at

<http://www.gfbronline.com/PDFs/GFBR9.pdf>

The Maori and Pacific customs and traditions were integrated effectively into the forum, including through conference dinners, which helped understand their importance to local communities. The need for progressive engagement with, and inclusion of indigenous and vulnerable populations in decision making about the framing as well as conduct of research was highlighted through examples. Issues discussed covered recent controversies in research like the Trovan trial in Nigeria and biopiracy of indigenous resources. The proactive provision of spaces and opportunities for forum participants to provide their inputs and feedback was very useful. The forum highlighted the diversity of conceptions of what it meant to be indigenous and vulnerable, but also showcased the challenges and successes in various parts of the world in working in this area.

ANANT BHAN was a participant from India at GFBR-9.

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### Announcements:

#### WHO Pan-Asian Workshop:

#### Addressing Ethical Issues in National Pandemic Influenza Planning

Thammasat University, Bangkok, Thailand, 09-12 June 2009

#### 10th Global Summit of National Bioethics Advisory Bodies

Singapore, 26-27 July 2010.

*For more information please contact the local organizing committee:*

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