



World Health  
Organization

# Ethics and Health Unit Newsletter

Contents	Page
Interview with Dr Marie-Paule Kieny	1
Ethics & TB	2
Global Summit of National Bioethics Advisory Bodies	3
Organ transplantation	3
Global Network of WHO Collaborating Centres for Bioethics	4
UN Inter-Agency Committee on Bioethics	4

## “Health Ethics: A critical dimension of WHO’s work”

Dr Marie-Paule Kieny was appointed WHO Assistant Director-General for Innovation, Information, Evidence and Research in October 2010. In this short interview, she shares her vision of ethics at WHO.

### How does the work of the Ethics and Health Unit feature in your vision for the Innovation, Information, Evidence and Research cluster?

Health ethics is a critical dimension of the work of WHO. All programmes deal with vulnerable populations, would they be minority groups, children, elderly or others, and we have therefore a duty to ensure that policies and interventions recommended by the Organization provide fair access to health services. The work of the Ethics and Health Unit operates in this general environment, and provides a centre of gravity for the discussion of a wide range of ethical and bioethical issues.

Of particular importance to the Innovation, Information, Evidence and Research cluster is the work of the Ethics and Health Unit on ethical aspects of research with human beings, including ethical review of research activities conducted by WHO staff. Another area of particular relevance to the overall mission of the cluster is the development of standards, tools and best practices for ethics review.

### How can the WHO best assist the development of stronger research ethics review mechanisms in lower income countries?

The Ethics and Health Unit, including the Ethical Review Committee secretariat in Geneva is very engaged with our colleagues in WHO Regional Offices, and has organized and participated over the past years in numerous training workshops on research ethics review. Collaboration across WHO Headquarters and Regional Offices and with networks of ethics review committees in low and middle income countries should be enhanced in order to facilitate access to strategic information, to foster knowledge sharing and to increase the sustainability of WHO's capacity strengthening investments in this area.



### What do you envisage will be the key ethical issues in research ethics over the next decade?

Without having to consult my crystal ball, I have no doubt that many ethical aspects of health research, like those relating to the use of placebo in clinical trials, will continue to be discussed with passion. Research related to human cloning is another topic for which ethical consensus is far from reach.

#### From the Editor:

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

#### How to contact us:

Ethics and Health Unit  
Department of Ethics, Equity,  
Trade and Human Rights  
World Health Organization  
WHO/IER/ETH  
Avenue Appia 20  
CH-1211 Geneva 27  
Switzerland

[ethics@who.int](mailto:ethics@who.int)

<http://www.who.int/ethics>

#### Editorial team:

Marie-Charlotte Bouësseau

Andreas Reis

Ghassan Karam

Nawaz Ahmad (intern)

## New publication: ETH launches guidance document on Ethics and TB

The Ethics and Health Unit (ETX) is pleased to present their latest publication.

In December 2010, ETX and the Stop TB department at WHO jointly published the guidance document 'Guidance on ethics of tuberculosis prevention, care and control'. This publication represents the fruits of the taskforce on Ethics and TB established by ETX and the Stop TB department. This document is the first of its kind and is available in English here: [http://whqlibdoc.who.int/publications/2010/9789241500531\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf). It is currently being translated into the 5 other official UN languages.

At its second meeting in April 2008, the WHO Task Force on XDR-TB recommended the production of a guidance document on "Ethics of TB care and control". Following this recommendation, the Ethics and Health Unit of the Department of Ethics, Equity, Trade and Human Rights and the Stop TB Department jointly established a WHO Task Force on Addressing Ethical Issues in TB Care and Control Programmes in August 2008. Twenty-two members were nominated from a variety of fields, including National TB Programmes, Civil Society, Ethics, Human Rights and Health Law.

The aim was to undertake an analysis of selected priority ethical issues in TB and to support the development of WHO guidance in order to help governments and their national TB programmes, TB service providers, policy-makers and civil society and other stakeholders implement TB prevention, care and control efforts in an ethical manner.

Discussion papers on the following topics were commissioned and authored by experts on the taskforce:

- 1) Access to diagnosis and treatment
- 2) Obligations and rights of health-care workers and patients
- 3) Public health measures
- 4) Research.

These papers are in the process of being published in the International Journal of Tuberculosis and Lung Disease, in a special supplement on Ethics and Social Determinants of Health (June 2011).

The Task Force held its first meeting in December 2008 at the Joint Centre for Bioethics at the University of Toronto. Members discussed the background papers prepared for the meeting and the main points to be included in the global guidance document. The Task Force gathered again in August 2009 and drafted the outline for the guidance. In October 2009 a consultation with additional representatives of civil society and national TB programmes enabled further valuable input. A refined outline was endorsed by WHO's Strategic and Technical Advisory Group for Tuberculosis (STAG-TB) in November 2009, and received further input at the 40th Union World Conference on Lung Health in December 2009.

Since its publication, ETX has been working on several projects focusing on the implementation and dissemination of the guidelines.

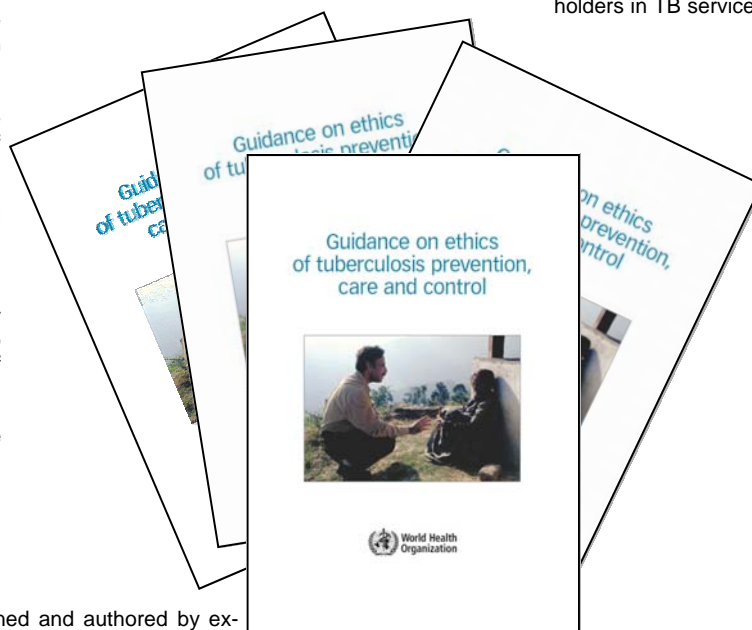
ETX has been organising on-site country workshops, delivered to disseminate the guidance material to national TB programme managers. As part of this, ETX has developed an annotated facilitator's guide with illustrative case studies for group discussion. These offer concrete examples of ethical dilemmas that decision-makers face in defining and pursuing TB policies and programmes, and illustrate some of the challenges and solutions proposed in the ethics guidance document. The first of these workshops took place in Athens and The Hague last year. In April 2011, a similar regional activity was organized in Guatemala, and the next workshop will be held in China 8-9 June 2011.

ETX is also in the process of developing an online training course on Ethics and TB, with the support of the University of Miami Ethics Programs, a WHO Collaborating Centre. It is envisaged that this training course will primarily target healthcare managers, policymakers, and national TB programmes. But the audience for this tool could also include other stakeholders in TB services such as frontline staff and healthcare workers involved in rendering TB services.

ETX and the Stop TB department are also developing mechanisms for monitoring the impact of this document. This monitoring framework will consider the extent to which, first, the ethics guidance has been incorporated into formal policies on the country and programme level; second, those policies actually being followed in day-to-day practice; and, finally, changes in policies and practice actually improve the lives and health of individuals and communities affected by TB, with attention to social justice considerations.

The chapters of the guidance document consider the following:

1. Overarching goals and ethics values
2. The obligation to provide access to TB services
3. Information, counselling and the role of consent
4. Supporting adherence to TB treatment
5. The gap between the availability of drug susceptibility testing and access to M/XDR-TB treatment
6. Healthcare workers rights and obligations
7. Involuntary isolation and detention as last-resort measures
8. Research on TB care and control



## THE GLOBAL SUMMIT OF NATIONAL BIOETHICS ADVISORY BODIES

The 8<sup>th</sup> Global Summit of National Bioethics Advisory Bodies was hosted by Singapore's Bioethics Advisory Committee and the Ministry of Health on the 26<sup>th</sup> and 27<sup>th</sup> of July 2010.



### 8<sup>th</sup> Global Summit of National Bioethics Advisory Bodies

26 to 27 July 2010



The Ethics & Health Unit of the WHO, which provides the Permanent Secretariat for these Global Summits, were joined by delegates representing the Council of Europe, the European Commission and the National Ethics Committees (NECs) of over 33 countries.

As part of a wide-ranging discussion, Dr Ruediger Krech, Director of the Department of Ethics, Equity, Trade and Human Rights at WHO noted that the presence of so many National Ethics Committees gave the Summit credibility in terms of being able to formulate directions for development.

He urged delegates to debate key issues in the hope of determining a common way forward and stressed that the WHO expected opinions and feedback from countries on major topics in bioethics, specifically:

- Organ transplantation and compliance with the guiding principles endorsed by all WHO Member States, during the last World Health Assembly in May 2010
- Functioning of Ethics Review Committees;
- Ethical issues in tuberculosis (TB) treatment and prevention;

- Biobanking and research on stored human biological materials
- Synthetic biology and its implications.

Recognising the imperative to discuss these topics and the essential need to maintain continuity across Global Summits, four working groups were es-

ablished at the Global Summit.

In the broadest terms, the working groups aim to explore, identify, collect and share information and opinions on the field relevant to each group. It is hoped that this will encourage interaction between National Bioethics Advisory Bodies between summits and facilitate analysis and policy formulation at every level.

The four working groups are as follows:

1. Working group on Research Ethics  
Co-ordinator: Christiane Druml (NEC Austria)
2. Working group on Organ, Tissue and Cell transplantation  
Co-ordinator: Sadek Beloucif (Advisory board of the French Biomedicine Agency)
3. Working group on Biobanking  
Co-ordinator: Nikolajs Zeps (NEC Australia)
4. Working group on TB prevention, treatment and control  
Co-ordinator: Bocar Kouyate (NEC Burkina Faso)

## Ethics of organ, tissue and cells: implementation of the resolution adopted by the World Health Assembly in 2010

The clinical practice of transplantation includes many of the thorniest problems in medical ethics. Care has both profound impact on patients' lives and poses some of the most troubling ethical questions confronting modern medicine. With an attention to philosophical implications, bioethics has yielded key respect for integrity/autonomy of a person, with the attention for an appropriate consent, free from moral, economic, politic, scientific, or social pressures. These elements are rooted on practical grounds, preventing abuses. Other ethical concerns claim a clear respect for *principles and values*. Among these, in the field of transplantation, the recent guiding principles on human organ transplantation adopted by the World Health Assembly in May 2010, represent a major medical and ethical progress. Careful attention of these proposals that unite humans should now lead to direct assessment of their practical applications. Sharing information about activities related to their implementation could be one of the main tasks during the next Global Summit of National Ethics Committees which will take place in September 2012 in Tunis. This meeting can also represent an opportunity to tackle difficult issues on questions where there is no consensus and where more discussion would be needed. More than 40 years after the recognition

of brain death, the recent consideration of a *cardiac death* that may lead to organ donation urges every country, rich or poor, to consider this new therapeutic possibility. Is 'Controlled' cardiac death (after withdrawal of active life-sustaining therapies) appropriate, and in the affirmative, under which conditions? Is 'Uncontrolled' cardiac death (in emergency situations during out-of-hospital cardiac arrest) feasible, both medically and ethically? These questions could be associated to the general imperative of promoting and ensuring the equity of both access to transplantation and to organ procurement, even if a simple answer cannot easily be predicted. For these difficult and sometimes highly emotional dilemmas, understanding and clarification of differences among scientists, physicians, legal experts and philosophers would be highly relevant in light of a trans-cultural approach to medical care.

**Dr Sadek Beloucif,**

Chair of the Advisory Board of the French Biomedicine Agency

**ANNOUNCEMENT:** The Tunisian National Committee of Medical Ethics will host the 9<sup>th</sup> Global Summit of National Ethics Committees on 26-27 September 2012 in Carthage, Tunisia.

## THE GLOBAL NETWORK OF WHO COLLABORATING CENTERS FOR BIOETHICS

### Designation of the Institute of Biomedical Ethics as a WHO Collaborating Centre for Bioethics

The Institute of Biomedical Ethics (IBME) at the University of Zurich has been designated a WHO Collaborating Centre for Bioethics. The inaugural event took place on 25-26 October 2010 at the University of Zurich. IBME joins five other institutions which form the Global Network of WHO Collaborating Centres for Bioethics.

The other institutions are:

- Joint Center for Bioethics, University of Toronto, Canada
- Centro Interdisciplinario de Estudios in Bioética, Santiago de Chile
- University of Miami Ethics Programs, Miami, USA
- Espace éthique AP-HP, Paris, France
- Centre for Philosophy and Public Ethics, Australian National University, Canberra, Australia

The Network supports the WHO Secretariat in implementing its mandated work in the field of ethics and health. It focuses its collaborative activity in three key domains: public health ethics, research ethics, and clinical ethics.

The inaugural event was opened by the Dean of the Medical Faculty at the University of Zurich, Professor Klaus Grätz, who referred to the significant achievements of the IBME such as the establishment of the first PhD program in Biomedical Ethics and Law in Switzerland.

Dr Rüdiger Krech, director of ETH at the WHO, stressed the great contribution the IBME is making to the Global Network of WHO Collaborating Centers for Bioethics, whilst Professor Biller-Andorno, director of the

IBME officially welcomed the designation and accepted the WHO flag from Dr Krech.

For the occasion of the WHO designation, the IBME organized and hosted an international workshop on "The role of health technology assessment agencies in national rationing policies: towards elements for best practice". The goal of the workshop was to debate the conceptual, methodological, legal and ethical challenges for national agencies involved in health resource allocation decisions as well as to start identifying essential elements for best practice. A highlight of this was the keynote talk on Technology Assessment and the U.S. "Affordable Care Act: It's About Ethics, Not Technology", by Professor Alex Capron, University of South California who is a previous director of WHO/ETH.



Dr Krech, Director of Ethics, Equity, Trade and Human Rights at WHO, and Professor Biller-Andorno, director of IBME

Participants included representatives from the relevant national institutions from France, Germany, the UK, Sweden, Austria, Switzerland and the Netherlands; key stakeholders such as patients' organizations, practitioners, the pharmaceutical and insurance industries as well as scholars from the fields of ethics, law, health, economics and medicine.

WHO staff from the Department of Ethics, Equity, Trade and Human Rights (ETH) made significant contributions emphasising the importance of health technology assessment in the global health context as well as the central concerns around equity. Lively discussion and excellent presentations made the workshop a great success.

For more information on the IBME: [http://www.ethik.uzh.ch/ibme\\_en.html](http://www.ethik.uzh.ch/ibme_en.html)

For more information on the Global Network of collaborating centers: [http://www.who.int/ethics/partnerships/global\\_network/en/index.html](http://www.who.int/ethics/partnerships/global_network/en/index.html).

**ANNOUNCEMENT: The 3rd meeting of the Global Network of WHO Collaborating Centres for Bioethics will take place in Zurich, Switzerland, on 18-19 August 2011**

## 10th meeting of the UN Inter-Agency Committee on Bioethics

The UN Inter-Agency Committee on Bioethics met for its tenth meeting at the UNESCO headquarters in Paris on 4-5<sup>th</sup> March 2011. Member organisations such as the WHO and UNESCO were in attendance alongside associate members such as the Council for Europe, the European Commission, the Organisation for Economic Co-operation and Development and the World Trade Organisation. Discussion centred on the theme 'genetic privacy and non-discrimination'.

The United Nations Economic and Social Council (ECOSOC) has previously considered, from a legal and ethical perspective, the implications of increasingly sophisticated technologies for genetic privacy and non-discrimination in fields such as medicine, employment and insurance.

The ECOSOC requested that UNESCO report on relevant developments in the field of genetic privacy and non-discrimination. In parallel with a consultation process with member states, UNESCO launched a consultation with the UN Interagency Committee on Bioethics.

The issue was discussed at the tenth meeting in advance of UNESCO's report to the ECOSOC and was guided by three expert guests: Dr Anne Cambon-Thomsen from the Department of Epidemiology and Public Health, University of Paul Sabatier - Toulouse III; Professor Aart Hendriks from the Institute of Public Law, Leiden University Law School; and Prof Carlos Romeo-Casabona from the University of Deusto and University of the Basque Country. All three offered penetrating insights in to the main ethical challenges surrounding genetic privacy, provided an analysis of the current contentions in the field and illustrated attempts at responding on a normative level to a perceived threat to genetic privacy and non-discrimination. This established the context for an energetic discussion which included consideration of the concept of 'genetic exceptionalism'.

UNESCO will report back to the ECOSOC later this year. The next meeting of the UNIACB is planned for March 2012.