



ETHICS AT THE WORLD HEALTH ORGANIZATION



Department of Ethics, Trade, Human Rights and Health Law

Alexander Capron, director

Marie Charlotte Bouesseau

Andreas Reis

more on www.who.int/ethics

Ethics Team Activities in 2004

The ethics team in the Department of Ethics, Trade, Human Rights, and Health Law (ETH) implements activities collaboratively with many departments at headquarters and in the regional and country offices, as well as with the human rights, trade, and health law teams within the Department. These efforts are concentrated in the following areas:

Ethics of health systems

ETH is engaged in the policy development for one of WHO's top priorities, to provide treatment to 3 million HIV/AIDS patients by 2005 (3 by 5 Initiative). The role of ETH is to advise partners in the Initiative on ethical issues in clinical care, standards of care, and equitable access, with a strong focus on the latter. In collaboration with others at WHO and UNAIDS, ETH held an international consultation on "Equitable Access to Care for HIV/AIDS" on 26-27 January 2004 (available at: http://www.who.int/ethics/en/equity_art_meeting_report_e.pdf). Based on this meeting and wide

consultation with experts and stakeholders globally, ETH led a team in producing a volume in the HIV Department's 3 by 5 publication series, *Guidance on Ethics and Equitable Access to HIV Treatment and Care* (http://www.who.int/ethics/en/ethics_equity_HIV_e.pdf).

- Regional follow-up meetings and the integration of the equity guidance into country missions and capacity-building activities are under way, with the aim of operationalizing the *Guidance* document. Monitoring and impact assessment tools are being developed in collaboration with other WHO departments and UNAIDS.
- The ethics and human rights teams in ETH are working with other units

concerned with health systems, gender discrimination, children's rights, poverty and other social determinants of health, and a wide range of other subjects to elaborate a set of core concepts (such as "equity," "poverty," etc.) for use across all programmes.

- Carrying forward the preliminary study conducted several years ago by WHO on *Ethical Choices in Long-Term Care: What Does Justice Require?* (2002), ETH is working with departments concerned with aging populations, disability, mental health, and nursing, as well as the Hastings Center, to develop a global perspective on the ethics of long-term care, particularly outside of institutions.

Public Health/ Population Ethics

- ETH has begun work with other departments and programmes, especially those concerned with WHO's global mechanisms of alert and response to disease outbreaks, to study the relationship between public health surveillance and research. It is also working with CIOIMS on the revision of its guidelines for epidemiological research.
- The dilemmas raised when screening programmes-in particular for cervical cancer-are conducted where adequate treatment is not available are being studied collaboratively with the cancer-control unit at HQ, along with regional input.

Ethics of Biotechnology

At the request of a Member State, ETH has prepared an information document, *Reproductive Cloning of Human Beings: Report on discussions in the United Nations General Assembly, for the January 2005 meeting of the Executive Board* (EB 115/INF.DOC./2).

- The report on Human Organ and Tissue Transplantation prepared by ETH together with the Department of Essential Health Technologies (WHO/HTP/EHT) for the Executive Board Meeting in January 2004 led to the adoption on 22 May 2004 by the 57th World Health Assembly of a resolution on the ethical and technical aspects of xenotransplantation as well as allogeneic trans-

plantation (especially the ethical and safety issues for compensated and uncompensated living kidney donors) (http://www.who.int/gb/ebwha/pdf_files/WHA57/A57_R18-en.pdf). ETH and EHT are now carrying forward the tasks set forth in that resolution through research and regional consultations. (Further information on the general subject and prior WHO work appears at http://www.who.int/ethics/topics/en/madrid_report_final.pdf.)

- A report on ETH's joint GIAN-funded project with the University of Geneva on "Human Genetic Databases: Towards a Global Ethical Framework" was presented at the 7th World Congress of Bioethics in Sydney, Australia, in November 2004.

Ethics of Research with Human Beings

- WHO has been engaged for many years in numerous activities in the field of research ethics, such as running workshops for research ethics committees and promulgating guidelines and standards (<http://www.who.int/ethics/research/>). For example, ETH is now collaborating with the Harvard School of Public Health and the Chinese Ministry of Health in a series of research ethics workshops in China, funded by the Fogarty International Center, National Institutes of Health, USA.
- Responding to requests from countries according to their needs, ETH contributed to the 1st international seminar on research ethics organised by the National Laboratory of Public Health of Congo in Brazzaville in June 2004 and to the regional meeting organised by National Bioethics Committee of Cyprus. The main objective of both activities was to establish a national ethical review process for research involving human subjects.
- A list of all national research ethics committees, which provide

policy advice to their governments and in some case review individual protocols, is posted on : http://www.who.int/ethics/en/Alphabetical_National_Bioethics_Committees_26November04.pdf

- ETH is a partner in the NEBRA project (Networking for Ethics on Biomedical Research in Africa) with a group of African and European institutions. This project, which is funded by the European Commission (6th Framework programme), will get underway in January 2005; it will involve the first comprehensive survey in 15 West African countries to establish the specific needs and resources of this region with regard to ethics review process at regional, national and local levels. Based on this inventory, a long term strategy will be established in collaboration with already existing African networks and institutions. Other similar initiatives are being discussed in interaction with EDCTP (the European-Developing Countries Clinical Trials Programme).
- ETH is part of the Steering Committee of the Global Forum for Bioethics in Research. The most recent Forum, hosted by INSERM in Paris in April 2004, was an occasion for 120 participants,

most of them from developing countries, to discuss the issue of benefit-sharing in research. The Sixth Forum, to be held in Blantyre (Malawi), in March 2005, will focus on the post-trial obligations of researchers and sponsors. (More information available at: <http://www.gfbronline.com/>).

- ETH is also co-leading the WICRAM project to develop the "WHO Intercultural Research Assessment Materials," in collaboration with WHO/TDR and Case Western Reserve University, Ohio. A comprehensive review of the literature and report have recently been completed and will serve as the basis for further work in this area.
- Within WHO, ETH provides leadership for the training workshops of the WHO Ethics Review Committee and assists on regional workshops with other technical departments such as the Department of Immunization, Vaccines and Biologicals and the special research programmes in reproductive health (RHR) and in tropical diseases (TDR). For the latter, it maintains the website of the Strategic Initiative for Developing Capacity in Ethical Review (SIDCER), a global activity of several regional fora of research ethics bodies (<http://www.who.int/sidcer/en/>).

Collaboration with other bodies and public dissemination

- ETH provides the permanent secretariat for the Global Summit of National Bioethics Advisory Bodies. The 5th Meeting, hosted by the Australian Health Ethics Committee in Canberra in Nov. 2004, provided an opportunity for 33 delegates from national bioethics committees to discuss a range of common concerns, including patenting and intellectual property in medical research, organ transplants from living donors, protection of participants in human research, research in indigenous populations, and end-of-life decisions. Presentations on recently completed projects were made by a

number of national committees on subjects such as stem cell research, living wills, and the insertion of human genes into other organisms. The next summit meeting will occur in Beijing in November 2006, though several of the committees are interested in carrying forward regional meetings in the meantime. (For more information see <http://www.who.int/ethics/globalsummit/en/>) ETH participates as an Observer in the plenary meetings of the Council of Europe's Steering Committee on Bioethics (CDBI) and is part of the Working Party preparing recommendations concerning research on human biological materials.

- Beth's webpage, which also provides information on trade, human rights, and health law

(<http://www.who.int/eth/en/>), has extensive materials and links on a range of bioethics topics, especially in research ethics.

- The Global Bioethics Calendar provides a comprehensive listing of events (<http://www.who.int/ethics/events/en/>), as well as a means of submitting items for inclusion on the calendar.
- ETH's program for interns and volunteers welcomes academics, practitioners, and healthcare professionals, as well as graduate and professional students, as Junior or Senior Ethics Fellows in the Department; in the course of a year, ten to fifteen fellows participate. (See <http://www.who.int/ethics/fellows/en/> for application information.)
- ETH represents WHO in the UN Inter-Agency Committee on Bioethics.

Professional Ethics

- Legal and health system barriers to the use of opioid drugs in palliative care are exacerbated by professional reluctance to use such drugs and other problems in the management of pain, especially at the end of life. This topic, which bridges health systems ethics and professional ethics has recently come onto the ETH agenda, as the ethics and human rights teams have become involved in an initiative to promote access to opioid drugs in palliative care in developing countries. Partners include other WHO departments, collaborating centres and the International Narcotics Control Board in Vienna. ETH will address equity in access, informed consent, cultural perceptions of, and barriers to, appropriate pain control, and end-of-life care.
- The potential for corruption exists throughout the process of developing, licensing, and using pharmaceuticals. ETH is beginning an examination of the issues of conflicts of interest for physicians, in research and prescription practices, as part of a larger study being carried out by the Department of Essential Drugs and Medicines Policy (EDM/HTP), in consultation with the World Medical Association.
- In resolution WHA 55.16 in 2002, the World Health Assembly signalled its concern with so-called "dual use" research and the need to develop containment strategies and global preparedness plans for deliberate misuses of developments in the life sciences. ETH is providing advice on ethics (in particular, by exploring the respective roles of "Codes of Ethics" and "Codes of Conduct") for the project being lead by the Department of Communicable Disease Surveillance and Response (CSR/CDS), in collaboration with other departments and national and international organizations.