NATIONAL ADVISORY BOARD ON RESEARCH ETHICS (TENK) Annual Report 2005

1. Mission of National Advisory Board on Research Ethics

The statutory tasks of the National Advisory Board on Research Ethics, which is appointed by the Ministry of Education, are:

- 1) To make proposals and issue statements to governmental authorities on legislative and other matters concerning research ethics;
- 2) To act as an expert body working towards the resolution of ethical issues relating to research;
- 3) To take initiative in advancing research ethics and to promote discussion concerning research ethics;
- 4) To follow international developments in the field and to take actively part in international cooperation; and
- 5) To inform the public about research ethics.

2. Composition of the Board

In 2005 the Chair of the Board was Chancellor Eero Vuorio (University of Turku) and the Vice-Chair Professor Jaana Hallamaa (University of Helsinki). The Secretary General was Salla Lötjönen, LL.D, M.A. and her substitute was Reetta Niemelä (17 January -15 July 2005) and Sari Löytökorpi, PhD (from 1 September 2006). The office of the Secretary-General is attached to the Federation of Finnish Learned Societies, previously situated at Mariankatu 5 C and since December 2005 in the House of Nobility, Hallituskatu 2 B.

The National Advisory Board on Research Ethics has eight members, who do not have personal deputies:

Professor Katie Eriksson, Åbo Akademi University Director Merja Hiltunen, National Technology Agency Tekes Professor Liisi Huhtala, University of Oulu Professor Juha Karhu, University of Lapland Director Paavo Löppönen, Academy of Finland Vice-President Sinimaaria Ranki, EVTEK University of Applied Sciences Professor Ari Salminen, University of Vaasa Professor Terttu Vartiainen, National Public Health Institute and University of Kuopio.

3. Activities

The Advisory Board convened seven times during 2005. The Board works to

- 1) prevent misconduct and fraud in science by disseminating information and arranging education and seminars on the principles of good scientific practice;
- 2) develop cooperation with universities and polytechnics and assist them and research institutes in arranging education about research ethics;
- 3) develop and monitor the investigation of ethical misconduct and fraud in research;
- 4) develop a distinct profile in disseminating public information about research ethics; and
- 5) contribute actively to Finnish and international debates on research ethics.

3.1 Preventive action and education

During 2005 the Board organised four training seminars:

The national ethics bodies subordinate to different ministries (the National Advisory Board on Research Ethics, the Cooperation Group for Laboratory Animal Sciences, the National Advisory Board on Health Care Ethics, the National Advisory Board for Biotechnology, the Board for Gene Technology) participated in the Science Days on 14 January with a joint programme *Bioterrori* — *uhkakuvat ja todellisuus* (Bio-terror - threat and reality). The event was chaired by Research Professor Matti Sarvas (National Advisory Board for Biotechnology). Presentations were delivered by Research Professor Pauli Leinikki (National Public Health Institute), Principal Medical Officer Simo Nikkari (Defence Forces), Professor Jouko Lönnqvist (University of Helsinki) and Research Professor Juhani Eskola (National Public Health Institute).

In addition, the national ethical bodies arranged public lectures on genetically modified plants and gene-food, industrial biotechnology, and questions relating to human genetic data at ChemBioFinland 2005 on 28 April 2005. The National Advisory Board for Biotechnology was responsible for the arrangements. Each lecture was attended by some 50 people.

On 31 May 2005 the national ethical bodies, together with TUTKAS, the association of researchers and MPs, arranged a round table negotiation as a follow-up to the seminar on Biotechnology – the state of the art and the future (24 November 2004). The memorandum can be accessed in Finnish at <u>http://www.protsv.fi/tenk/ajank.htm</u>.

On 31 August 2005 the National Advisory Board on Research Ethics organised an authorship seminar, which explored practices in publication and authorship in different disciplines. The event convened an audience of some 150, aroused a lively discussion, and had media exposure afterwards. The seminar was chaired by Chancellor Eero Vuorio. The seminar programme, with appendixes, is available in Finnish at http://www.protsv.fi/tenk/ajank.htm.

3.2 Cooperation with universities, polytechnics and research institutes

As in earlier years, the National Advisory Board received a number of requests from universities and polytechnics for research ethics education. The educational events in 2005 included Ethics and register-based research on 9 March, jointly organised with the Finnish Information Centre for Register Research and the Finnish Medical Association. Chancellor Eero Vuorio, Chair of the National Advisory Board, delivered the concluding paper. The Seminar was attended by some 30 persons and had points of contact with the seminars on biobanks arranged at Biomedicum and at the Parliament House in the autumn of 2004.

Considering research ethics education its key priority, but lacking the resources to respond to all requests for education, the National Advisory Board on Research Ethics arranged the aforementioned authorship seminar (see 3.1) on 31 August 2005. The Board intends to continue this line of indirectly helping ethics education rather than directly providing it in 2006, although it is obvious from the appendix that the members also give a great deal of organisation-specific education, which consumes resources from the Board's other activities.

3.3 Development of mechanisms for handling misconduct in research

During 2005 the National Advisory Board on Research Ethics was notified of three new cases of misconduct or fraud, two of which were handled locally. The Board was requested to give its opinion on one case, which concerned a decision made by the Rector of the University of Kuopio on alleged misconduct.

3.4 Publication and information

The National Advisory Board on Research Ethics continued its active dissemination of information on its web site and through the members' and the Secretary General's papers and articles, which were published on the web site.

The English translation of the brochure published in 2004 in Finnish, *Human stem cells, cloning and research*, jointly prepared by the national research ethics bodies, came out at the end of 2005. It can be accessed at <u>http://www.protsv.fi/tenk/publications.htm</u>.

The taskforce appointed to look into research ethics issues in the humanities and social sciences, which goes under the acronym HYMY, continued to work actively during 2005. It is composed of the Vice-Chair, Professor Jaana Hallamaa, Professor Irma Sorvali, Professor Veikko Launis and Dr Salla Lötjönen. In 2004 the taskforce outlined the structure of the book which will be published on research ethics in the humanities and social sciences and invited experts from different sectors as writers. By the end of 2005 most of the contributions were ready, and the book will be ready in August 2006.

The Board members and the Secretary General published a number of articles on research ethics and were interviewed for newspapers, periodicals, radio and television during 2005. Examples of these are Chancellor Eero Vuorio's editorial on the need for guidelines for writing curricula vitae in the periodical *Tieteessä tapahtuu* (Science now) 3/2005; Professor Katie Eriksson's interview in the Åbo Akademi University in-house magazine *Meddelanden* on 22 April 2005; Ari Salminen's interview in the Vaasa University in-house magazine *3*/2005, under the heading of "From research ethics to public administration ethics"; and Secretary-General Salla Lötjönen's article on the use of human biological samples in medical research in the periodical *Lakimies* (Lawyer) on 7 October 2005. The Board also received numerous international requests for information about its activities and composition, which have been answered as far as possible.

3.5 Statements issued, international activities and other cooperation

During 2005 the Board issued eight opinions and one statement:

- On 10 January 2005 an opinion requested by the EU Commission concerning the draft *Commission Recommendation on the European Charter for Researchers and on a Code of Conduct for the Recruitment of Researchers* dated 14 December 2004
- On 22 March 2005 an opinion requested by the Ministry of Education concerning the UNESCO's *Preliminary Draft Declaration on Universal Norms on Bioethics* dated 9 February 2005
- On 8 April 2005 an opinion requested by the Ministry of Education concerning *Commission Recommendation on the European Charter for Researchers and on a Code of Conduct for the Recruitment of Researchers* adopted by the Commission on 11 March 2005
- On 29 April 2005 an opinion requested by the Ministry for Foreign Affairs concerning the Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine
- On 10 May 2005 Chancellor Eero Vuorio participated in the hearing on the amendment of the Act on laboratory animals and the Act on the protection of animals
- On 20 May 2005 an opinion requested by the Ministry of Education concerning the social sciences section in the UNESCO Programme and Budget
- On 24 May 2005 and 7 September 2005 opinions requested by the Ministry of Education concerning UNESCO's *Preliminary Draft Declaration on Universal Norms on Bioethics* dated 9 February 2005 and 24 June 2005 and the debate conducted in Finland concerning the proposed declaration
- On 7 September 2005 an opinion requested by the Ministry of Education concerning the draft International Declaration on Science Ethics to serve as a basis for an ethical code of conduct for scientists.

The National Advisory Board on Research Ethics was active in international matters during 2005:

- Secretary General Reetta Niemelä attended meetings on the preparation of the UNESCO declaration on bioethical norms in Paris in January, April and June 2005 and reported to the Ministry of Education and the National Advisory Board on Research Ethics.
- The Chair attended the meeting of the European Conference of National Ethics Committees 25—26 April 2005.
- The Chair contributed to the international conference on Responsible Conduct of Research in Warsaw as an invited expert and as the chair of the panel on authorship.
- Secretary General Salla Lötjönen participated in the work of the Nordic bioethics committee.
- Secretary General Sari Löytökorpi attended the Sixth European Forum of National Ethics Councils, NEC-Forum meeting in London 17-18 November 2005
- Secretary General Sari Löytökorpi attended the meeting of the Network of Research Ethics Committees in Nordic Countries and Adjacent Areas: Planning Activities Meeting in Vilna, Lithuania, 24-26 November 2005

In 2005 the Board cooperated actively with the other national ethics bodies. The Secretary General participated in the activities of the national support group for the Science and Society programme coordinated by the Academy of Finland.

4 Personnel and finance

In 2005, the National Advisory Board on Research Ethics had only one full-time employee, Secretary General Salla Lötjönen and her substitutes Reetta Niemelä (17 January -15 July 2005) and Sari Löytökorpi (from 1 September 2006). In 2005, the Board had the use of the telephone exchange, computer and caretaker services of the Federation of Finnish Learned Societies.

The Ministry of Education had granted an operational appropriation of \notin 33,400 to the National Advisory Board on Research Ethics for 2005: \notin 8,400 for running costs and \notin 25,000 for publication and seminars. These funds were administered by the Ministry of Education. The salary and clerical funds (\notin 55,600) were administered by the Federation of Finnish Learned Societies.

This annual report for 2005 was adopted at the Board's meeting on 2 February 2006.

Eero Vuorio Chair Sari Löytökorpi Secretary General

Appendix

List of events attended and papers read by the members and Secretary General of the National Advisory Board on Research Ethics in 2005

- 9 March, Chancellor Eero Vuorio participated in a seminar on ethics and registerbased research arranged by the Finnish Information Centre for Register Research and the Finnish Medical Association.
- 14 March, University of Tampere course on good scientific practice and the handling of violations; Secretary General Reetta Niemelä.
- 16 March, University of Lapland Graduate School course on good scientific practice and the handling of violations; Professor Juha Karhu.
- 22-23 March, Virtual University Days; Chancellor Eero Vuorio.
- 7 April, National Graduate School in Law, research ethics event, Professor Juha Karhu.
- 12 May, National patient insurance day "Good and safe care", Helsinki; Vice-Chair Jaana Hallamaa on the expectations of the patient.
- 29 May -2 June, International Conference on Science Law Ethics, Medical Research – Human Rights, 60 years after the 2nd World War, University of Haifa; Director Paavo Löppönen.
- 31 May, Session of the National Graduate School in Informational and Structural Biology on good scientific practice and the handling of violations; Chancellor Eero Vuorio.
- 31 August, Authorship seminar organised by the National Advisory Board on Research Ethics, Chancellor Eero Vuorio on medicine, biosciences and natural sciences; Professor Juha Karhu on questions relating to open access publication.
- 7-8 September, Biobanks seminar in Taiwan; Secretary General Salla Lötjönen as an invited expert.
- 8-9 September, Conference on The European Charter for Researchers and the Code of Conduct for their Recruitment: turning policy into practice. London, UK; Chancellor Eero Vuorio.
- 28 September, Seminar of the national ethical bodies; Chancellor Eero Vuorio on topical issues concerning biobanks.
- 12 October, Seminar on the Politics of Biobanking; Chancellor Eero Vuorio, Senior Technology Adviser Merja Hiltunen, Secretary General Sari Löytökorpi.
- 6-7 November, Nordic Biolaw Focus on Assisted Reproduction organised by the Nordic Committee on Bioethics; Secretary General Salla Lötjönen on *Overview and introduction to the biolaw tables: biolaw & biobanks*.
- 11 November 2005, seminar *Tiede tutuksi* organised by the Finnish Cultural Foundation, the Committee for Public Information and the National Advisory Board on Research Ethics; Chancellor Eero Vuorio on the research ethics viewpoint in scientific communication.
- 17-18 November, Sixth European Forum of National Ethics Councils, London, UK; Secretary General Sari Löytökorpi
- 24-26 November, Meeting of the Network of Research Ethics Committees in Nordic Countries and Adjacent Areas; Secretary General Sari Löytökorpi.