

National Advisory Board on Research Ethics

TENK

Annual report 2004

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

The composition of the National Advisory Board on Research Ethics changed at the end of January 2004. From 1 to 31 January 2004 the Board was chaired by Rector Gustav Björkstrand (Åbo Akademi University) and the Vice-Chair was Professor Jaana Hallamaa (University of Helsinki). The Secretary General was Salla Lötjönen, LL.M., M.A. The Board's office was attached to the Federation of Finnish Learned Societies.

From **1 February 2001 to 31 January 2004** the Board had eight members and a permanent expert, Adjunct Professor Marja Simonsuuri-Sorsa. The members, who did not have personal deputies, were:

Secretary General Arja Kallio, Academy of Finland
Special Researcher Veikko Launis, University of Turku
Professor Olli Mäenpää, University of Helsinki
Senior Assistant Sinikka Parkkinen, University of Joensuu
Professor Amos Pasternack, University of Tampere
Research Professor Matti Sarvas, National Public Health Institute
Director Mervi Sibakov, National Technology Agency Tekes
Professor Irma Sorvali, University of Oulu.

The composition was almost completely changed in 2004. The new Board (1 February 2004-31 January 2007) is chaired by Chancellor Eero Vuorio (University of Turku). Professor Jaana Hallamaa (University of Helsinki) continues as Vice-Chair and Salla Lötjönen, LL.M., M.A. (from 19 November 2004 LL.D) as Secretary General. The office was relocated from the main building of the Federation of Finnish Learned Societies to a totally renovated building in the inner court, which is better suited to the Board's needs.

The new composition of the National Advisory Board on Research Ethics is:

Professor Katie Eriksson, Åbo Akademi University
 Senior Technology Adviser Merja Hiltunen, National Technology Agency Tekes
 Professor Liisi Huhtala, University of Oulu
 Professor Juha Karhu, University of Lapland
 Director Paavo Löppönen, Academy of Finland
 Research Manager Sinimaaria Ranki, Helia, Helsinki Business Polytechnic
 Professor Ari Salminen, University of Vaasa
 Professor Terttu Vartiainen, National Public Health Institute and University of Kuopio.

3. Activities

The Board convened seven times during 2004 to perform its tasks as outlined in its statute (1) preventing misconduct and fraud in science by disseminating information and arranging education and seminars on the principles of good scientific practice; (2) developing cooperation with universities and polytechnics and assisting them and research institutes in arranging education about research ethics; (3) developing and monitoring the investigation of ethical misconduct and fraud in research; (4) developing a distinct profile in disseminating public information about research ethics; and (5) contributing actively to Finnish and international debates on research ethics.

3.1 Preventive action and education

During 2004, the Board organised five training seminars. At the Finnish Medical Convention, 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) jointly arranged two half-day seminars on 7 January 2004 under the headings of "Research physicians' economic linkages" and "Human stem cells in patient care and research". Both seminars were well attended.

Further, the National Advisory Board on Research Ethics, together with the Academy of Finland, arranged a seminar on "Research ethics for supervisors and mentors" on 30 January 2004. The purpose was to convene persons responsible for research ethics education in different organisations and graduate schools, present different aspects of research ethics to them and provide them with knowledge and skills needed to arrange research ethics education in their organisations. Another aim was to promote networking between research ethics educators in different organisations.

The national ethics bodies jointly arranged an open whole-day seminar on biobanks at Biomedicum on 20 September 2004. The seminar was very popular and there are plans for arranging a follow-up seminar around the same theme in 2005. Biobanks were also touched upon at the seminar "Biotechnology — the state of the art and the future" arranged by the national ethics bodies together with the Society of Researchers and MPs at the House of Parliament on 24 November 2004. This seminar convened a large audience from both academic and political circles. In addition to these seminars, the ethical bodies cooperated with the Committee for Public Information at the Turku Science Fair on 1 October 2004, where they shared a booth and offered a joint programme of panel discussions. The panel consisted of Chancellor Eero Vuorio, the Chair of the National Advisory Board on Research Ethics, Adjunct

Professor (Docent) Veikko Launis and Senior Researcher Kirsti Ala-Mutka, Tampere University of Technology.

3.2 Cooperation with universities, polytechnics and research institutes

As in previous years, the National Advisory Board on Research Ethics received a large number of requests for research ethics education from universities and polytechnics. An education event was arranged for the archaeologists of the University of Turku on 3 March 2004. Board members contributed to the lecture series "Research and ethics" of the National Public Health Institute on 2 April and 7 May 2004 and gave lectures at the University of Art and Design Helsinki on 22 September, at the Finnish Institute of Occupational Health on 23 September and on the "Clinical researchers" course at the University of Tampere on 14 October. Board members also participated in education events arranged by graduate schools, e.g. the Future Electronics Programme, the National Graduate School in Psychology, the postgraduate and continuing education programme of the Paediatric Neurology Unit of the Helsinki University Central Hospital, and postgraduate seminars of the Turku University Hospital. A list of the education events and the participating Board members is appended.

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 seminar on "Research ethics for supervisors and mentors" on 30 January 2004 (see 3.1). The Board intends to continue this line of indirectly helping ethics education rather than directly providing it, 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.

During 2004, another four research organisations registered their commitment to the Ethical Guidelines (2002) issued by the National Advisory Board on Research Ethics, which makes a total of 76 commitments. A new, slightly revised edition of the Guidelines was published in 2004 (see 3.4 Publication and information).

3.3 Development of mechanisms for handling misconduct in research

During 2004 the National Advisory Board on Research Ethics was notified of seven new cases of misconduct or fraud, three of which were handled locally. The Board was requested to give its opinion on three cases of alleged misconduct. In addition to these, the Board gave its opinion on a case submitted in 2003.

The cases handled by the Board between 1998 and 2004 are presented in a statistical form below (Table 1). The alleged cases of misconduct or fraud reported to the Board include notifications of cases adjudicated by research organisations, as provided in the Guidelines, and cases notified directly to the Board by the person requesting the Board's opinion. The cases handled by the Board only include those in which it has given its opinion on an alleged violation or has recommended reappraisal by the research organisation. The statistic does not contain requests for opinion in cases which the Board has forwarded to be primarily handled locally. The figures are indicative only since the data on all locally treated cases are not available and the statistical principles have not been identical in all years.

CASES HANDLED BY AND NOTIFIED TO THE NATIONAL ADVISORY BOARD ON RESEARCH ETHICS 1998 – 2004 (Table 1)

	1998	1999	2000	2001	2002	2003	2004
Plagiarism		5(4)[1]	1(0)[1]	2(1)[0]	6(0)[5]	0(0)[0]	1(0)[0]
Misappropriation of an original research idea, plan or finding	3(3)[0]	4(3)[0]	1(1)	2(1)[0]	1(1)[0]	2(0)[0]	1(0)[0]
Fabrication or misrepresentation of research findings	1(1)[0]	1(1)[0]	2(1)[0]	1(1)[0]	0(0)[0]		1(1)[0]
Misrepresentation of facts or of research merits in application		2(2)[0]		0(0)[0]	1(0)[0]		
Misconduct in science	2(1)[1]	1(0)[0]	7(1)[0]	2(1)[1]	1(1)[0]	3(1)[2]	3(2)[3]
Other violation of good scientific practice		6 (2)[0]			3(1)[0]	1(0)[0]	1(1)[1]
TOTAL	6(5)[1]	19(12)[1]	10(2)[1]	7(4)[1]	12(3)[5]	6(1)[2]	7(4)[4]

Reported to the Board X
 Processed by the Board (X)
 Noted fraud/misconduct [X]

The requests handled by the National Advisory Board on Research Ethics concerned:

- Exchange of information between two researchers and the reliability of documents, and the right instance for the handling of the matter. The board noted that the exchanged documents were not yet advanced enough to be considered actual research findings and did not recommend further investigations;
- The propriety of a research team leader's actions as regards research materials and the administration of the research. The Board concurred with the university that the leader was guilty of misconduct in science and did not consider the investigating officials disqualified;
- The procedures of a university in handling a matter which the rector had seen to constitute a violation of good scientific practice. The Board underscored the importance of hearing both parties already at the preliminary inquiry stage, but since both parties had been offered an opportunity to be appropriately heard, did not recommend further investigation.
- The procedures of a university in handling a matter which the rector had seen to constitute misconduct in science. The Board did not find anything to reproach in the university's procedures.

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 site. The brochure "*Ihmisen kantasolut, kloonauksen ja tutkimus*" (Human stem cells, cloning and research), which was jointly drafted by the national ethics bodies, was published at the stem cell seminar held at the Finnish Medical Convention in January 2004. The seminar was also televised by the Finnish Broadcasting Company YLE. The

guidelines Good scientific practice and procedures for handling misconduct and fraud in science published by the National Advisory Board on Research Ethics in 2002 was reprinted with minor revisions mainly concerning the wording and some references to legislation, which were not seen to require a new adoption procedure.

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 2004. It is composed of the Vice-Chair, Professor Jaana Hallamaa, Professor Irma Sorvali and Special Researcher Veikko Launis, with the Board's Secretary General as its secretary. In 2004 the taskforce outlined the structure of a book on research ethics in the humanities and social sciences and invited experts from different sectors as writers. Some of the contributions had been submitted by the end of 2004, and the book will come out during 2005. The HYMY taskforce also wrote a response to a letter to the editor published on 17 June 2004 in *Helsingin Sanomat* (the largest daily in Finland), which questioned the ethics of social sciences.

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 2004. Examples of these are Irma Sorvali's article "*Etiikan opetus pohjoismaisissa kielissä*" (Ethics teaching in Nordic languages) published on the web on 26 July 2004; Ari Salminen's "*Hyvän hallinnon etiikka – kolmen profession arvioita hallinto- ja johtamistyön eettisistä kysymyksistä*" (Good administrative ethics – Three professions' assessments on ethical issues in administration and management, University of Vaasa, 2004); Research Manager Sinimaaria Ranki's television interview in "*Verkkoyhteys*" (Net connection) programme on YLE in October 2004; and the Secretary General's doctoral dissertation published in May 2005 "*Lääketieteellinen tutkimus ihmisillä – oikeudellisia ja eettisiä näkökohtia ruumiilliseen koskemattomuuteen puuttumisesta lääketieteellisessä tutkimuksessa*" (Medical research on humans — legal and ethical aspects on encroaching physical integrity in medical research, Forum Iuris, University of Helsinki 2004). 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 2004 the Board issued four opinions and one report:

- 1) An opinion for the Ministry of Education concerning the preparation of the UNESCO Declaration on Universal Norms on Bioethics (11 March 2004, in cooperation with the other ethical bodies),
- 2) A report (18 March 2004) for the Parliamentary Social Affairs and Health Committee concerning amendments to the Medical Research Act and the Medicinal Drugs Act (Government Proposal 20/2004),
- 3) An opinion for the Ministry of Agriculture and Forestry concerning the draft Bill for a Laboratory Animals Act and for an Act Amending the Protection of Animals Act (29 April 2004),
- 4) An opinion for the Ministry of Education concerning a committee report on Science and society (21 October 2004),
- 5) An opinion for the Ministry of Education concerning the third outline of the UNESCO Declaration on Universal Norms on Bioethics (18 November 2004).

The National Advisory Board on Research Ethics was very active in international matters during 2004. The Secretary General acted as liaison in cooperation between national ethics boards, which was initiated by the European Commission and largely operates through

meetings arranged every six months. The 2004 meetings were held in Dublin and Amsterdam. The Secretary General was also invited as a member of the ethics sub-committee of the International Stem Cell Forum, which is a cooperation and coordination body for organisations funding stem cell research.

Cooperation with areas adjacent to Finland was facilitated by the fact that the Board Chair, Chancellor Eero Vuorio presided over a two-day research ethics workshop arranged by the cooperation network of the Baltic Sea Region universities and the Secretary General is one of the two Finnish members on the Nordic bioethics committee.

In 2004 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 2004, the National Advisory Board on Research Ethics had only one full-time employee, Secretary General Salla Lötjönen. In 2004, the Board had the use of auxiliary staff of the Federation of Finnish Learned Societies for filing in addition to its telephone exchange, computer and caretaker services. The archival services were provided by Ms Kaisa Pulliainen 15 December 2003 - 9 January 2004.

The Ministry of Education had granted an operational appropriation of €18,400 to the National Advisory Board on Research Ethics for 2004: € 8,400 for running costs and € 10,000 for publication and seminars. These funds were administered by the Ministry of Education. The salary and clerical funds (€53,600) were administered by the Federation of Finnish Learned Societies.

This annual report for 2004 was adopted at the Board's meeting on 2 February 2005.

Eero Vuorio
Chair

Reetta Niemelä
Secretary General

List of lectures and papers by the members and Secretary General of the National Advisory Board on Research Ethics in 2004

Finnish Medical Convention 7 January 2004

Secretary General Salla Lötjönen on embryonic stem cell research and Finnish legislation

Professor Jaana Hallamaa on human stem cells and ethical issues

Research ethics for supervisors and mentors, a seminar, 30 January 2004

Rector Gustav Björkstrand on the tasks of the National Advisory Board on Research Ethics and the role of research ethics education

Secretary General Salla Lötjönen on the situation in research ethics in Finland and abroad

Archaeology and research ethics, 3 March 2004

Secretary General Salla Lötjönen on good scientific practice and its violations

Future electronics research programme, Research scientist seminar, 25 March 2004

Secretary General Salla Lötjönen on "What is 'good scientific practice'?"

National Public Health Institute, 2 April 2004

Secretary General Salla Lötjönen on good scientific practice and prevention of misconduct in science

Presentation of the services of the Federation of Finnish Learned Societies, 28 April 2004

Secretary General Salla Lötjönen on the National Advisory Board on Research Ethics

A lecture series of the national ethics bodies, 5 May 2004

Secretary General Salla Lötjönen on emergency examinations and examinations of persons of reduced competency

National Public Health Institute, 7 May 2004

Professor Terttu Vartiainen on a good research plan and successful grant application

Graduate School in Psychology, 13 May 2004

Secretary General Salla Lötjönen on good scientific practice in research

World Congress in Medical Law, 5.8.2004

Secretary General Salla Lötjönen on "Children and Medical Research" and "Personal Integrity and Medical Research"

University of Art and Design Helsinki, 22 September 2004

Secretary General Salla Lötjönen on the situation in research ethics in Finland and abroad

Finnish Institute of Occupational Health, 23 September 2004

Secretary General Salla Lötjönen on information-based consent in clinical medical research

A seminar of the national ethics bodies, 27 September 2004

Secretary General Salla Lötjönen on control group studies and ethical considerations

University of Helsinki, 16 September 2004

Secretary General Salla Lötjönen on medical and bio law

University of Helsinki, 23 September 2004
Secretary General Salla Lötjönen on medical research on humans

Turku Science Fair, 1 October 2004
Chancellor Eero Vuorio in a panel on plagiarism and research ethics

Norwegian National Ethical Committee, 12 October 2004
Secretary General Salla Lötjönen on "Regulation of medical research with persons of reduced competency"

University of Tampere, 14 October 2004
Secretary General Salla Lötjönen on statutes governing general clinical research

Baltic Sea seminar, Turku 12 November 2004
Chancellor Eero Vuorio on "The Finnish System of National and Local Ethical Boards"
Secretary General Salla Lötjönen on "National Advisory Board on Research Ethics in Finland"

Helsinki University Central Hospital, Paediatric Neurology Unit, 16 November 2004
Secretary General Salla Lötjönen on law and ethics in medical research on children

Turku University Central Hospital, 23 November 2004
Secretary General Salla Lötjönen on the researcher's law package

Biotechnology – the state of the art and the future, 24 November 2004
Chancellor Eero Vuorio on biobanks and genebanks
Secretary General Salla Lötjönen's comment on the purpose of and need for normative regulation

University of Helsinki, 16.12.2004
Secretary General Salla Lötjönen on universities and the handling of research ethics problems