

*The National Advisory Board*  
**on Health Care Ethics (ETENE)  
and ETENE's Sub-Committee on  
Medical Research Ethics (TUKIJA)**



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## The National Advisory Board on Health Care Ethics (ETENE) and ETENE's Sub-Committee on Medical Research Ethics (TUKIJA)

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ETENE was established in 1998 by incorporating the Advisory Board into the Act on the Status and Rights of Patients (amendment 330/1998 of 15 May 1998). This was preceded by extensive discussion in the Finnish Parliament concerning the importance, duties and goals of such a multi-disciplinary forum. At the end of the millennium, rapid development of medical technology, increased opportunities, limited resources, internationalisation and many other rapid changes on the level of society as a whole increased the need to establish a multidisciplinary advisory board.

The composition and duties of ETENE are described in the Decree on the National Advisory Board on Health Care Ethics (494/1998 of 26 May 1998). The Advisory Board comprises a chairperson, a vice chairperson and 18 other members, each of whom has a personal deputy. The members of the Advisory Board are healthcare service users and providers, healthcare professionals, and representatives of various scientific disciplines such as law, medicine, nursing science and ethics. According to the Decree, four members of ETENE are appointed from among the Members of Parliament.

The Government appoints the Advisory Board for a four-year term. The mission of the Advisory Board is to handle ethical issues relating to healthcare and the status of patients *from the perspective of principles*. Its mission is to promote ethical discussion on the level of society in matters relating to healthcare. The Advisory Board provides expert assistance with the development of healthcare legislation. It also collects and distributes information on ethical issues relating to healthcare and on international ethical discourse relating to healthcare. ETENE follows the development of healthcare and technology from the viewpoint of ethics. It can issue statements and recommendations and propose initiatives in issues it considers important. The Advisory Board is a discussion forum, not a decision-making body.

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ETENE meets six times a year and also organises an annual internal one-day seminar. The Advisory Board can appoint sub-committees and working groups that handle specific ethical issues. ETENE collaborates with the other national ethical advisory boards in Finland, e.g. by organising joint training sessions and preparing publications. The Advisory Board also collaborates with e.g. other healthcare organisations, professional organisations, hospital districts, universities and county governments by organising training sessions. The Advisory Board has a website at <http://www.etene.org/e/>. Minutes of ETENE meetings, statements, publications and contact information of other actors in the field are available at the website. ETENE also collaborates with the national ethics committees of other countries.

Central issues in ETENE's work have included the realisation of patients' rights, equity and human dignity in healthcare. In its many publications, ETENE has discussed equity, the right of self-determination, and ethical boundaries in healthcare. ETENE has also often discussed issues relating to death and end-of-life care, as well as issues relating to mental health, and particularly the line between abandonment and the right of self-determination in mental health disturbances and drug dependency. New technology and new research methods are also important discussion topics in ETENE.

## ETENE's Sub-Committee on Medical Research Ethics (TUKIJA)

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The mission of ETENE's Sub-Committee on Medical Research Ethics (TUKIJA) is to assess ethical issues relating to clinical studies carried out as international multicentre studies, and to issue national opinions on them. TUKIJA can also delegate the task of evaluating a study protocol to the Ethics Committees of hospital districts. TUKIJA's duties also include supporting regional Ethics Committees in handling matters of principle relating to research ethics, and organising training. TUKIJA organises training for, and in collaboration with, members of Ethics Committees, researchers, and other parties working in the field of medical research.

TUKIJA comprises a chairperson, a vice chairperson and nine members. Each member has a personal deputy. The members represent pharmaceutical research, various medical specialties, genetic research, epidemiology, jurisprudence, ethics and patients. TUKIJA has an executive secretary.

TUKIJA meets once a month. The schedule for TUKIJA meetings, as well as the request deadlines for advisory opinions and pre-evaluations directed at TUKIJA, are available at the TUKIJA website, <http://www.etene.org/e/tukija/>. The TUKIJA website also includes instructions about completing these requests, the contact information of the Ethics Committees of hospital districts, and other up-to-date information about TUKIJA's operations and matters of principle concerning medical research ethics.



## ETENE 1 October 2002–30 September 2006

### **Chairperson**

Paula Kokkonen  
Senior Lawyer, Deputy Mayor  
Helsinki

### **Vice Chairperson**

Leena Niinistö  
Chief Physician  
Katriina Hospital, Vantaa

### **General Secretary**

Ritva Halila  
M.D., Ph.D., Specialist in Paediatrics  
[ritva.halila@stm.fi](mailto:ritva.halila@stm.fi)

A comprehensive list of ETENE's members and deputy members is available at the ETENE website at <http://www.etene.org/e/members.shtml>

Minutes of ETENE meetings, statements, and ETENE working group reports are also available at the ETENE website at <http://www.etene.org/e/documents.shtml>. Communications can also be directly sent to ETENE from the feedback page at <http://www.etene.org/e/yourturn.shtml>.

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## TUKIJA 1 October 2002–30 September 2006

### **Chairperson**

Raimo Pekkanen  
Justice of the Supreme Administrative  
Court, Doctor of Laws  
Espoo

### **Vice Chairperson**

Helena Kääriäinen  
Professor  
University of Turku

### **Executive Secretary**

Outi Konttinen  
Master of Social Sciences  
[outi.konttinen@stm.fi](mailto:outi.konttinen@stm.fi)

A comprehensive list of TUKIJA's members and deputy members is available at the TUKIJA website at [http://www.etene.org/e/tukija/tukija\\_members.shtml](http://www.etene.org/e/tukija/tukija_members.shtml).

TUKIJA working group reports, instructions, recommendations and publications are also available at the ETENE website, [http://www.etene.org/e/tukija/tukija\\_documents.shtml](http://www.etene.org/e/tukija/tukija_documents.shtml). Electronic requests for pre-evaluations should be submitted to TUKIJA by email: [etene@stm.fi](mailto:etene@stm.fi).

## ETENE-publications

### ETENE seminar publications:

- Oikeudenmukaisuus ja ihmisarvo suomalaisessa terveydenhuollossa.** (2001) Sosiaali- ja terveysministeriön selvityksiä ISSN 1236-2115; 2001;1 ISBN 952-00-0913-2 (Equity and human dignity in health care in Finland). In Finnish, summary in English
- Kuolemaan liittyvät eettiset kysymykset terveydenhuollossa.** (2002) ETENE-julkaisuja ISSN 1458-6193;4 ISBN 952-00-1086-6 (Ethical issues related to death in health care). In Finnish, summary in English
- Hoidon hinta ja tasa-arvo terveydenhuollon eettisenä haasteena.** (2003) ETENE-julkaisuja ISSN 1458-6193;6 ISBN 952-00-1269-9 (Price of care and equality as an ethical challenge in health care) In Finnish, summary in English
- Autonomia ja heitteillejätö – eettistä rajankäyntiä.** (2004) ETENE-julkaisuja ISSN 1458-6193;10 ISBN 952-00-1458-6 (Borderline between autonomy and abandonment from the ethical point of view). In Finnish, summary in English
- Monikulttuurisuus Suomen terveydenhuollossa.** (2005) ETENE-julkaisuja ISSN 1458-6193;11 ISBN 952-00-1642-2 (Multiculturalism in Finnish Health Care). In Finnish, summary in English

### Shared ethical principles in health care:

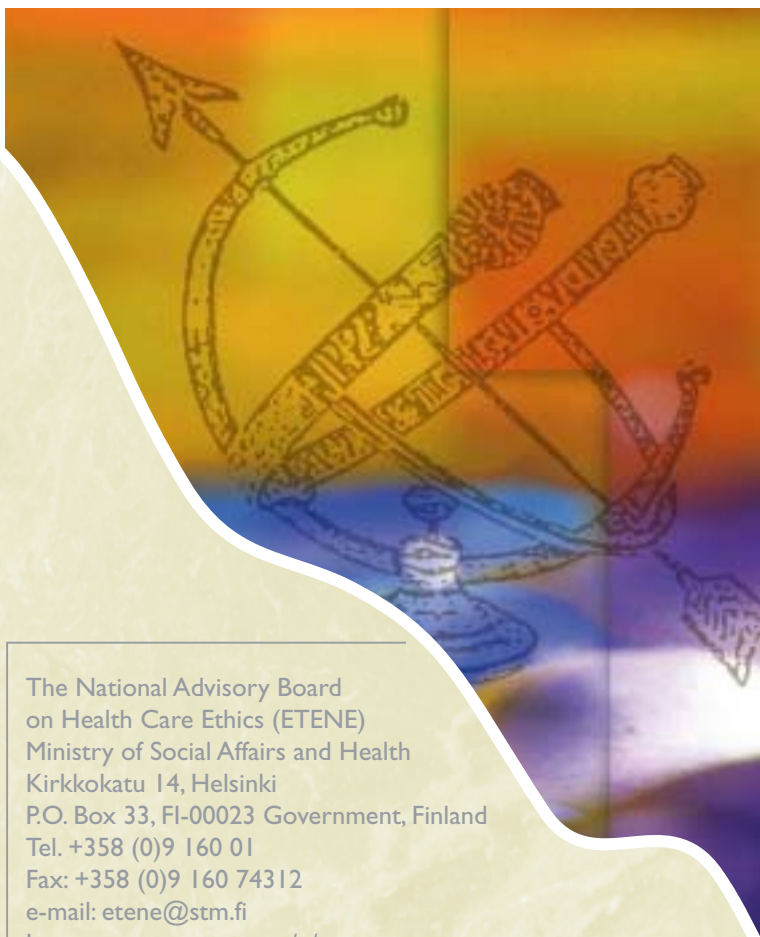
- Terveydenhuollon yhteinen arvopohja, yhteiset tavoitteet ja periaatteet.** (2001) ETENE-julkaisuja ISSN 1458-6193;1 ISBN 952-00-1076-9
- Gemensam värdegrund, gemensamma mål och gemensamma principer för hälso- och sjukvården.** (2001) ETENE-julkaisuja ISSN 1458-6193;2 ISBN 952-00-1077-7
- Shared Values in Health Care, Common Goals and Principles.** (2001) ETENE-julkaisuja ISSN 1458-6193;3 ISBN 952-00-1078-3

### Other publications and reports:

- Eettisyyttä terveydenhuoltoon. Valtakunnallinen terveydenhuollon eettinen neuvottelukunta 1998–2002.** (2003) ETENE-julkaisuja ISSN 1458-6193;5 ISBN 952-00-1257-5 (Ethics in Health Care. The National Advisory Board on Health Care Ethics 1998-2002). In Finnish, summary in English
- TUKIJA 1999–2002. ETENE/Lääketeiteellinen tutkimuseettinen jaosto.** (2003) ETENE-julkaisuja ISSN 1458-6193;7 ISBN 952-00-1299-0 (TUKIJA 1999–2002. ETENE/Sub-Committee on Medical Research Ethics. Serial publication). In Finnish, summary in English
- Saattohoito – Valtakunnallisen terveydenhuollon eettisen neuvottelukunnan (ETENE) muistio.** (2004) ETENE-julkaisuja ISSN 1458-6193;8 ISBN 952-00-1435-7
- Vård i livets slutskede – Promemoria utgiven av riksomfattande etiska delegationen inom hälso- och sjukvården (ETENE).** (2004) ETENE-julkaisuja ISSN 1458-6193;9 ISBN 952-00-1436-5
- End-of-life care – memorandum of the National Advisory Board on Health Care Ethics.** In: [http://www.etene.org/dokumentit/saattohoito\\_eng.pdf](http://www.etene.org/dokumentit/saattohoito_eng.pdf) (pdf only)

### Joint publications of national ethical advisory boards:

- Tutkimuksen eettinen arviointi Suomessa – Etisk invärdering av forskning i Finland.** (2002) ISBN 952-442-966-7
- Ethics Evaluation of Research in Finland.** (2002) ISBN 952-442-967-5
- Ihmisen kantasolut, kloonaus ja tutkimus.** (2003) ISBN 952-442-678-1
- Human stem cells, cloning and research.** (2005) ISBN 952-00-1817-4



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