

From Philosophical Ethics, Bioethics and Medical Ethics to the Ethics of Science and New Technologies

**An overview of the research projects of the Centre
for Ethics, 2006–2011**

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The Centre for Ethics of the University of Tartu is a consortium whose mission rests on three pillars: interdisciplinary research, teaching, and working with the public. Since our first major anniversary, we have continued our research from where it left off – with a primary emphasis on bioethics, which continues to be a topic of great social resonance. We have also expanded into other areas of practical ethics, and our network of international cooperation has expanded beyond Europe to include ethics centres in the USA and Asia. Nevertheless, the Centre

for Ethics does not consider it necessary to cover all the bases of interdisciplinary research, nor to include all areas and problematics in its purview. Our focus is rather on involving a large number of people, joining forces in building up the field of study and thereby providing impetus for a continued engagement with ethics-related research. What follows is an overview of interdisciplinary research of the Centre for Ethics in the last five years.

Philosophical Ethics

The Centre for Ethics of the University of Tartu engages in close research cooperation with the Institute of Philosophy and Semiotics of the University of Tartu. Both institutions participated in a joint target-financed research project **“Normativity: a critical study of its philosophical foundations, historical sources and forms of manifestation”**, which focused on normativity in morality, politics, law, religion, and art, that is on the different forms of the manifestation of normativity throughout history and today. The project provided a comprehensive account of the philosophical foundations, historical origin and ways of manifestation of normativity in thinking, scholarship and society. The goal was to verify and analyse critically the widespread view in contemporary philosophy that concepts such as knowledge, truth, meaning, virtue, justice, good and right have a normative dimension. The project was based on a philosophical-anthropological hypothesis, namely that the sources of normative thinking and acting are to be found in human nature. We engage in normative thinking because we are reasonable beings with the capacity to reflect on our beliefs and desires, and to ask, what one should do and how one should live.

“Critical analysis of relativism and pluralism regarding truth and knowledge, norms and values” is a target-financed research project beginning in 2008 and continuing through the end of 2013.

This project will critically analyze various implications and forms of both relativism and pluralism (moral, political, epistemic, conceptual). The term “relativism” refers to an array of positions unified by the view that certain important aspects of thought, experience, judgment and reality are relative. Pluralism signifies a perspective that certain

things (concepts, values, norms, discourses, views) exist in plurality. The purpose is to show that denial of monism – the view that there exists only one acceptable truth or value system – does not necessarily lead us to relativism. In fact, there is a great deal of inconsistency and incoherence within relativism. Consistent pursuit of a relativist position can lead to a denial of objectivity, knowledge, communication and the possibility of progress in thinking, language, science, morality, politics and other fields. A critical analysis of relativism must indicate whether pluralism – which also stands in opposition to monism – would be a sufficient alternative – when combined with objectivism. Practical philosophy examines the nature, bases and hierarchy of values, addressing the problem of values incompatibility, and the solving of values conflicts.

Medical Ethics and Bioethics

The research grant of the Estonian Science Foundation “**The ethical aspects of genetic databases and new technologies: individual versus common values and goods**” continued to explore philosophical and ethical questions that have emerged along with rapid developments in science and technology. The more specific focus was on the ethical aspects of genetic databases and the related, so-called new technologies which were examined both philosophically and sociologically. The main focus of the research was on values. Distinction was made between individual and common, and universal and particular values. What makes the question significant is the fact that values are directly related to moral functioning. Also, concepts such as justice, solidarity, privacy, tolerance, trust and patriotism were systematically studied. The project took a closer look at what these concepts actually mean and whether they are individual or common values.

The research came to the conclusion that values are objective, but the way they are expressed depends on cultural and religious traditions. At the same time, values are related to economic and political developments and perceptions of what constitutes a good life. These circumstances make it necessary to address the context of values in order to understand their content. It was also found that there is no point

in making a comparison between individual and common values, as a value can be both individual and common. The study of values and risks associated with the development of science and the so-called new technologies, specifically values related to gene banks, revealed that trust plays a central role. Analysis showed that there is a need for rational trust which is based on people's autonomous choices and requires information, while pointing out why irrational or blind trust is not acceptable.

The word "trust" can be used when speaking about people and institutions, as it presumes mutual relationship. Trust, in turn, has a number of different manifestations. *Simple* or *naive* trust means that the other person has not offered it, but it is taken for granted. Simple trust cannot be clearly expressed or nor can it be reflected upon. *Basic trust* is built upon simple trust; it provides a basis for shaping a personality and forms a person's attitude towards the world. *Blind trust*, unlike simple trust, is not innocent, but rather irrational—people see, but at the same time refuse to see. Irrational blind trust is characterised by an unwillingness to take into consideration the arguments and clear evidence of the opposing party. *Authentic trust* is open to evidence and is the result of experiences, purposefulness, and commitment. Trust means taking risks, because it is impossible to know whether the other party will do what is expected. This is why we need authentic trust, which is reflective and includes reasonable choices.

The project also examined the sharing of goods and pointed out that it is necessary to distinguish between two levels: 1) a level associated with a specific research project, and 2) a level which concerns continuing unequal access to scientific and technological achievements throughout the world. It is important to look beyond the discourse of medical research and to involve political arguments, applying these in a global context and thus counterbalancing the profit-oriented paradigm in biotechnology.

In addition, the project examined the values of Estonian people and ways in which the risks associated with new technologies are perceived. A qualitative study (focus groups) was carried out in order to investigate the relationship between peoples' attitudes and the general world of values and the argumentation behind these attitudes.

In addressing genetic science and technology, the research underscored four aspects:

- 1) Genetic science was favoured, above all, due to the new therapeutic possibilities it created. The effectiveness of new treatment methods outweighed possible ethical uncertainties. In other areas, the attitudes were more critical.
- 2) There was a clear distinction between the healing and ameliorative applications of gene technology. The latter were considered unnatural (e.g. chip or gene therapy).
- 3) Existing technologies were regarded as more justified than possible developments in the future. Here, too, it was found that extensions and applications could be unnatural, while existing technologies were justified.
- 4) Comparison of different age groups showed that younger people addressed the issues in a more abstract way and expressed, above all, principled opposition, whereas the middle-aged and older generation were more optimistic and found that the benefits or effective treatment resulting from the use of new technologies could outweigh possible uncertainties. Such results may be based on the fact that older people have had personal contact with serious diseases for which no effective treatment exists.

The project **“An expert opinion about the handling of personal data connected to the electronic medical record in the context of bioethics and medical ethics”** constituted a set of activities carried out within the framework of the public procurement “Changes in legal jurisdiction necessary for the implementation of the e-health project”. The work was done by the working group of the Centre for Ethics and the Tartu University Hospital which was composed of Arvo Tikk, Margit Sutrop, Andres Soosaar, Raul Talvik, Tiina Talvik, Raul-Allan Kiiwet, Mati Rahu, Merje Tikk, Mart Einasto, and Jaan Ginter.

In 2006 and 2007, the working group:

- 1) formed an expert opinion about the ethical choices and issues related to the draft act on the health information system⁵ and the possible solutions to these issues,

⁵ A version of 06.10.06 of the draft act on the health information system, considering the changes of 01.12.06 and 10.12.06.

- 2) worked with the Estonian Medical Association, the Estonian Nurses Union, and the Estonian Hospitals Association, to develop the Guidelines for Good Practice to inform patients about the processing of their personal data in the health care system,
- 3) provided an opinion on the Estonian Code of Medical Ethics and made suggestions on how to supplement the document according to different situations related to the provision of health care services.

The research group drew a distinction between personal and social use of health information. Personal use was understood as the use of health information for therapeutic purposes and for exercising the rights of data subjects. Social use was understood as the promotion of public health, including the development of health and health care policies; management of health care and the provision of health care services; quality control for health care; scientific and applied research and the need for statistics, and the use by other offices for the protection of society, if the patient's medical condition poses a danger to society.

The working group outlined arguments for and against the position of informed consent; weighed the position of personal autonomy fixed in the draft act with the experience of international medical ethics in the matter, and possible scenarios for the functioning of electronic health records; it was concluded that the patient's informed consent is necessary in order to ensure personal autonomy and effective functioning of electronic health records.

The recommended informed consent is limited to the use of electronic health record data for the purposes of patient care and does not include the collection of data which could take place without consent. According to the working group, the social use of non-personal data should be possible without the consent of data subjects.

The working group found that the creation of a nationwide database and the transmission of data to health information system have basically led to a new situation that requires a different approach. It is therefore recommended that one-time informed consent be obtained from a patient at his or her entry point to the health information system, which would allow the data to be used for therapeutic purposes. This would significantly enhance the autonomy of patients and re-

inforce the trust between the patient, the health care system and the state. The preferred solution or the process of informed consent would take place during the patient's first outpatient visit or hospitalisation after the activation of the electronic health record system and would be valid until it is withdrawn. Although this option takes time and effort and leads to additional costs to the health care system (e.g. the number of patients seen decreases, appointment times get longer), it is the only way to make sure that the information actually reaches the patient. The process of obtaining informed consent should be thorough and should take place once, and it should be documented at the health information system (HIS).

The working group also found that people should be made aware of the health information system (HIS) in several ways. First of all, it is necessary to inform the general public through public media. Further, information on the health information system must be available in all health care institutions. For this purpose, the working group prepared a leaflet. As patients usually turn to doctors, the working group found it necessary to develop more comprehensive guidance materials for health care providers. The guidance materials provide answers to and explanations for any questions related to health information system. The working group prepared an information leaflet for patients, an information sheet and informed consent template for use in in-patient medical institutions, and guidance materials for health care providers in relation to HIS.

The draft act on health information system and its analysis were abandoned. However matters connected to the health care information system were regulated by means of supplementing the Health Care Services Organisation Act and accompanying implementation legislation.

After the completion of the ETF project and public procurement, the Centre for Ethics moved on to ethical issues related to genetic and e-health databases in the context of the European Economic Area (EEA) Financial Mechanism grant "**New ethical frameworks for genome banks and e-health databases**" (01.04.2008–31.12.2008), which focused on ethical frameworks. The project analysed in detail all aspects of new ethical frameworks related to genome banks and electronic health record databases. For the first time, ethical frameworks

implemented in the field of biometrics were examined. It was observed that, in the context of new scientific and technological developments, we are moving from informed consent, which is characteristic of interventional studies, to open consent, which has become a common practice in biobanking, and thence to no consent, as in the field of e-health and biometrics.

It was demonstrated that the need for new ethical frameworks for genetic databases, electronic health record and biometrics can, on the one hand, be justified by developments in science and technology and, on the other hand, by values shift – from individual to common values. Also, the rapid development of information and communication technologies has created opportunities for collecting and processing data on an unprecedented scale, and thus the (full) protection of privacy has become impossible. It has been pointed out that the risks associated with databases are not as serious as in the case of interventional medical research, and that the abovementioned developments have led to new opportunities for the promotion of common goods (such as knowledge or health). It has been found that this leads to a situation where the individual rights-based ethics must be replaced by common goods-based ethics.

In the context of both genetic and electronic health record databases, ethical dilemmas were explored that arose from the conflict between the values of liberal individualism and communitarianism. It was found that there is no need to set liberal and communitarian frameworks in opposition to each other. First of all, this would ultimately turn the debate into an argument about ideologies. Secondly, this is not normatively desirable, since it would leave individual rights unprotected. It is necessary to find a way to connect individual rights with common goods. This opportunity is provided by neo-communitarianism, according to which individual rights can only be based on our understanding of the common good. Therefore, rights do not take precedence over goods, as liberals believe. A communitarian turn is rewarding in the sense that it refers to the need to define the primary values, those which we cannot give up under any circumstances. It was also pointed out that setting up a contrast between individual and common values is often artificial; the public-private conflict of interest could be reconceptualised simply as the conflict between two personal

interests (e.g. a personal interest in the protection of privacy on the one hand and a personal interest in the promotion of common values – health or safety – on the other hand).

It was pointed out that instead of contrasting liberal and communitarian values, we should view them both in a pluralist setting. It was recognised that there are no absolute values, but only a number of objective values (e.g. privacy, autonomy, solidarity, benevolence) which, depending on the situation, can be differently perceived or, in some cases, come into conflict with each other, because they cannot be respected simultaneously. According to pluralism, the ranking of values is possible only in certain situations (for example, taking into consideration the characteristics of certain disciplines or socio-political context), because they depend both on facts of reality as well as on the traditions that surround us and individual perceptions of a good life. Common goods that lead us to individual rights can be derived from universal human nature. Individual rights need protection, especially when there is no democracy. It was demonstrated that new ethical frameworks should be developed taking into account the different levels of democracy in the world. A communitarian turn in bioethics may be beneficial in old democracies, but may be accompanied by several risks for new democracies and leave patients without protection in totalitarian regimes.

The project studied the experiences and expectations of the direct users of electronic medical records – doctors and patients. The focus group interviews focused on three main topics:

- 1) the changing nature of information exchange (how does the accessibility of health information for patients and doctors change the way information is presented; the problems of deciding what is the adequate amount of information to be recorded),
- 2) changes in the privacy of patient data regarding the possibility of access to health information via the health information system. This change is balanced by the ability of patients to see who has viewed their data,
- 3) changes in the doctor-patient relationship with regard to the fact that all information recorded by the doctor can be accessed by the patient and other doctors; also, the increased autonomy and responsibility of the patient regarding access to health information

without interpretation and help from the doctor. The doctors' concern is related to the increase in the number of possible complaints, whereas patients are worried about the fact that sensitive information that was previously known to one doctor only becomes available to everyone. This would lead to reduced privacy and issues of trust in relation to other doctors and the system.

The most notable contribution of the project was the comparison of different scientific and technological developments – gene banking, the e-health project, biometric databases – argument that the abandonment of informed consent leads to the disregard of autonomy. However, this is not in the public interest, since it would result in a loss of trust in researchers and policy makers. In the context of the project, two high-level international conferences were held in 2008 and 2010 in Tartu. In November 2010, the Centre for Ethics together with the Faculty of Philosophy of the University of Tartu, the Estonian Genome Centre of the University of Tartu, the Graduate School in Biomedicine and Biotechnology, and the Doctoral School of Behavioural, Social and Health Sciences organised a conference entitled “From informed consent to no consent? The challenges of new ethical frameworks”. The presentations given at the conference appear in a special issue of *Cambridge Quarterly of Healthcare Ethics*. The special issue was edited by Margit Sutrop and Kadri Simm.

The grant was a joint project between the researchers of the Centre for Ethics of the University of Tartu, the Centre for Ethics of the University of Iceland (Vilhjálmur Árnason) and the University of Bergen (Roger Strand and Kjetil Rommetveit).

The Centre for Ethics also participates in other projects related to bioethics and medical ethics. Examples include the grant of the Estonian Genome Centre of the University of Tartu and Prof. Andres Metspalu “**OpenGENE – Opening Estonian Genome Project for European Research Area**”. This grant includes an ethics component and three years of collaboration with the Centre for Ethics beginning in December 2009. In order to raise public awareness of ethical issues related to gene banks and to increase people's trust towards data banks, the grant entails the organisation of two international ethics conferences. The first conference was held in November 2010 in collaboration with

the Doctoral School of Behavioural, Social and Health Sciences and the EEA project “**New ethical frameworks for genome banks and e-health databases**”. The presentations given at the conference appear in a special issue of *Cambridge Quarterly of Healthcare Ethics* in 2011. The second international conference will take place in 2012. Also, in order to support the mobility of researchers and promote cooperation, the researchers at the Centre for Ethics have the opportunity to give presentations at international conferences.

Activities in the field of medical ethics and bioethics have also been carried out within the framework of **the Nordic Network for Philosophy of Medicine and Medical Ethics** (2009–2011), grant holder Prof. Lennart Nordenfelt, Linköping University. The presentations were given at the opening conference in Linköping. The final conference of the project will be held in Vilnius in October 2011, where scientific presentations will be accompanied by discussions on future cooperation possibilities and the possible establishment of a Nordic/Baltic society for philosophy of medicine.

Ethics of New Technologies

A Transdisciplinary Approach to the Emerging Challenges of Novel Technologies: Lifeworld and Imaginaries in Foresight and Ethics (01.03.2009–31.11.2011) (TECHNOLIFE)

The TECHNOLIFE project aims to develop new ethical frameworks to address ethical concerns of Europeans in relation to three technological fields. These fields are ICT-s, Geographical Imaging Systems and technologies to enhance the human body. The project will examine how the ethical concerns of different groups, communities and individual citizens can be considered in the EC policy in these three technological fields.

The project aims to propose a novel approach to research on ethical frameworks by the end of 2011. The concept of imagined communities is used as a means to arrive at ethical considerations without unduly suppressing the complexity, heterogeneity and communicatively challenging character of communities. The emphasis on information, communication and enhancing technologies is appropriate, since these add

momentum to the ongoing restructuring of social groups and perceptions, and shape the future of Europe. They also transform the very meaning of human sociability, identity, communication and community in ways that pose great challenges to ethical theories and ethics for policy.

The main perceptions, ethical considerations and technological developments were described by a number of disciplines. These descriptions were fed into an online database where they can be used by a number of relevant groups and communities. The results of the process will be analysed and interpreted to identify key perceptions and their related arguments and viewpoints among the relevant groups.

The qualitative data will then be used to:

- 1) develop new ethical frameworks fitted to the social and analytic level of imagined communities,
- 2) provide guidelines for the EC on policy in the three technological fields,
- 3) establish a web portal that can be used for further discussions on the three fields,
- 4) supply documentation on the overall process to be used for the development of ethical frameworks in other technological fields.

The project is coordinated by Prof. Roger Strand and Dr. Kjetil Rommetveit from the University of Bergen in Norway. The Centre for Ethics prepared the analysis "Ethical mapping of biometric technologies" and Prof. Margit Sutrop and Katrin Laas-Mikko wrote an article entitled "Risks and benefits of biometrics for surveillance: from identity verification to behaviour prediction". In spring 2011, an analysis of the ethical aspects of biometrics was launched, taking into account the results of the projects so far, and the outcome of which will be a publication in an international scientific journal.

Rising pan-European and International Awareness of Biometrics and Security Ethics (01.03.2009–28.02.2012)

Rising pan-European and International Awareness of Biometrics and Security Ethics (RISE) is a 36-month Coordination and Support Action which aims to promote pan-European and international awareness on the ethical aspects of biometrics and security technologies. In particu-

lar, the project aims to deepen, expand, and sustain intra-European and international dialogue already instigated by the international conferences on ethics and biometrics organised by the EC DG Research and the US DHS Privacy Office respectively in Brussels and Washington DC in 2005 and 2006. RISE's framework is the new political landscape created by the Treaty of Lisbon of the European Union. The EU is now on the verge of a multifaceted reform of its decision-making rules for security, which may have deep ethical and political implications. RISE will address these issues.

The project is based on three main ideas:

- dialogue must be global,
- operating policies must take into account ethical aspects, and
- conversation must be ongoing.

These ideas have led to the generation of three strategic objectives:

- preparing and holding a third international conference in China,
- preparing and holding a multi-stakeholder conference in Europe, Brussels, and
- preparing and holding a fourth international conference in Brussels.

The project is coordinated by Dr. Emilio Mordini from the Centre for Science, Society and Citizenship in Italy. The Centre for Ethics organised the second stakeholders' workshop, "Ethical and Policy Implications of Global Mobility and Security" in Brussels. Speakers included Mr. Siim Kallas, Vice-President of the European Commission, and Transport Commissioner; Mr. Jaak Aaviksoo, Estonian Minister of Defense; and Mr Peter Hustinx, European Data Protection Supervisor. The sub-themes of the workshop were: "Identity Management: Governance and Policy Making", "Fundamental Rights, Privacy and Security: A Multifaceted Prism" and "Critical Information Infrastructure Protection: The Ethical and Policy Context". Each year, the Centre for Ethics has to write an annual report on policies. Furthermore, a joint publication with Greek researchers from the Aristotle University of Thessaloniki, "New multimodal biometric technologies and morally problematic notion of identity" will be completed in 2011.

Ethics of Science and its Application

ETHICSWEB – Interconnected European Information and Documentation System for Ethics and Science: European Ethics Documentation Centre (01.06.2008–31.08.2011)

By the end of August 2011, a documentation centre holding ethics-related documentation from all over the Europe will be established. The centre therefore provides comprehensive information on ethics. The project is coordinated by Dr. Dirk Lanzerath from the German Reference Centre for Ethics in the Life Sciences (DRZE). The overall aim of the project is to promote democratic debate on ethical issues in science.

In order to meet those objectives, an ethics web was created which:

- provides comprehensive information on ethics,
- enables to connect existing operations,
- reflects the European cooperation programs in order to promote joint activities between countries,
- promotes the involvement of civil society in the debate on ethical issues.

ETHICSWEB is a well established web-based infrastructure which brings together ethics-related information provided by different European countries, regional centres and international organisations.

The Centre for Ethics of the University of Tartu took the role of a regional observer, whose task was to map the situation in neighbouring countries and to identify new potential partners. Together with partners from the University of Maastricht, a survey was conducted on databases and portals which collect information on the centres for ethics and the possibilities of linking or integrating them. Together with partners from the University of Vilnius, a compendium was prepared which is intended to provide guidance to those whose goal is to create and sustain the new ethics documentation centre.

See: <http://ethicsweb.org>

Children as Change Agents for Science in Society (SiSCatalyst, 01.01.2011–31.12.2014)

In January 2011, the 7th framework programme project “**Children as Change Agents for Science in Society**” began. The project is coordinated by Tricia Jenkins, MBE from the University of Liverpool in the UK. The project seeks to identify how children can be change agents in the relationship between science and society, and from this starting point, to indicate how they can be catalysts in the long-term solutions to the great social challenges of their future. The focus will be on capable children who are currently least likely to pursue the study of science at the post secondary level.

The Centre for Ethics manages an ethics-centred work package, the main task of which is to evaluate and consider the ethical aspects of the project, to ensure and improve the overall quality of the project, and to develop guidelines which stress the ethical aspects of situations involving children.

Summary

Over the past five years, interdisciplinary research in the Centre for Ethics has expanded substantially, both in terms of the number of subjects covered and the number of projects in process, which is very positive. Thus it is important to continue these activities, involve new people and widen the range of topics covered. It is important that an awareness of the importance of ethics take root in all disciplines of the sciences. Interdisciplinary research in various areas of practical ethics enhances our understanding of what kind of values should be protected under which circumstances, identifies the possible consequences of such action, and enables us to have a say in the development of relevant policies.