



THE DANISH
COUNCIL OF
ETHICS

Annual Report 2013



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Preface

2013 was a year when a number of the Danish Council of Ethics' activities targeted the young people of Denmark, the next generation of adults to make up their minds about the ethical dilemmas being raised in the fields of health, nature, environment and food.

2013 has seen the Ethical Forum for Young People, which addresses the eldest elementary school forms, deal with the challenges that can affect young people suffering from mental illness. Under the heading "In or out? About ethics and mental illness" the Council focused on the relations that young people with mental illness engage in – or do not engage in perhaps – given that it can be hard for mentally vulnerable young people to engage in the relations others may take for granted. The material was sent out to all elementary schools in Denmark and has been praised for involving the youngsters' own voices, and for daring to give voice to a dilemma that can be difficult for many people to get to grips with.

That topic formed a natural continuation of the Council's earlier work on "Power and Powerlessness in Psychiatry", the purpose of which was to create visibility and generate debate around the conditions and challenges encountered by people afflicted by mental illness.

Within the domain of nature, the environment and food, the Council launched a new set of teaching material on bioenergy in 2013 for both upper-secondary and elementary schools. The material takes its cue from the Council's report on bioenergy, food and ethics, and under the heading of "Bioenergy – climate-friendly energy source or food thief?" considers the dilemmas raised when account has to be taken of the climate, the environment, those alive at present, future generations and the poorest people in the world. The teaching material is part of "Ethics and the Building Blocks of Life", which publishes teaching material every other year.

In parallel with this the Council has launched a set of teaching material about the ethical dilemmas raised as a result of doctors', researchers' and private companies' increasing use of extensive genetic examinations – aka genome tests. The material is an extension of the Council's work on the difficult subject that was completed with a statement in late 2012.

One topic that generated great debate both nationally and internationally was the report entitled "International trade in human eggs, surrogacy and organs". As its jumping-off point this investigative work takes the fact that childless people and those with kidney failure now have the option of travelling to other countries and buying human eggs, surrogacy or kidney operations. The Council wished to shed light on the ethical dilemmas stemming from this globalization and generate debate around it.

In December 2013 the Council presented the report in the Danish Parliament with the participation of a number of politicians, experts and citizens.

No one can doubt that priority-setting in the Danish health service is an important social matter. Under the heading "Ethics and priority-setting – why it's so difficult" the Council presented an anthology which seeks to answer the questions concerning which values and which ethics to use as a basis for priority-setting. The contributions to the anthology have been penned by some of the country's leading experts and practitioners, who with their special insight and knowledge of the topic have given their vision of how to set priorities and what considerations and values to take as a basis.

The Council's key missions are to generate debate and advise Danish Parliament. The debate-generating activities require the Council to be capable of reaching out to a number of different target groups. The Council's members therefore take turns to attend more than 100 debating events every year arranged by organizations and as-

sociations around the country wishing to debate the many ethical questions being considered by the Council. Acting in an advisory capacity to Danish Parliament thus calls for the Council to prepare the groundwork thoroughly, so that members of parliament are presented with all the essential ethical considerations to enable politicians to make the necessary political decisions. The chosen topics for the year have helped to do both.

Enjoy the read!

Jacob Birkler
Chairman

Christa Kjøller
Head of Secretariat



Ethics and priority-setting in the Danish health service – why it's so difficult

ANTHOLOGY The Danish health service is under great financial pressure and very careful consideration therefore has to be given to what to spend its resources on. In April 2013 the Council published an anthology which, by means of different contributions, attempts to answer the questions: Which values and which ethics should be used as a basis for prioritizing? How to lend visibility to who makes the priority-setting decisions – and why?

The Danish health service is one of the flagships of the Danish welfare society, which is precisely what creates problems when it is very difficult to gain a complete overview of the way priorities are set in the Danish health service and the reasoning behind it.

Spotting who makes popular decisions about improvements to treatment options and facilities is easy, but working out how it has come about that other areas are underprioritized and underresourced is another thing altogether.

Priority downgrades in the Danish health service give the impression of being something insidious that happens of its own accord. There is no transparency around those who have made decisions about them. But that is not so in reality. Downgrading is a result of decisions.

Any debate will dry up if it is impossible for patients and citizens to work out who has taken the decisions to downgrade priority for an area and on what grounds. In a democracy there should be the possibility of debating whether priority-setting is being done correctly and on the basis of values which its citizens can largely endorse. It should be possible for the individual citizen to vote for a politician whose views are shared by that citizen.

Everything indicates that it is going to be even more imperative to set health service priorities in the future. Health services that could have been of great importance to citizens' health will have to be "deselected". For that reason the Danish Council of Ethics considers it particularly urgent to generate debate about two entirely fundamental subjects: One is how the priority-setting process actually works, and how it can be made more visible, how the concrete priorities come about. The other subject is which values to base such priorities on.

The anthology is built from four themed blocks (the priority-setting process, expensive medicines, user fees and lifestyle diseases), containing contributions by people from widely divergent backgrounds – politicians, philosophers, health professionals, economists etc. – who from widely divergent perspectives express their position on at least one of the two subjects. In addition the anthology includes a background paper on future developments in health spending and conversations between members of the Council.

Four themed blocks



International trade in human eggs, surrogacy and organs

REPORT Infertile people and those with kidney failure can travel to other countries and pay their way to buying human eggs, surrogacy or kidney operations. This globalization of health services entails a number of ethical dilemmas on which the Danish Council of Ethics has wished to shed light and generate debate. In December 2013 the Council published the report *International Trade in Human Eggs, Surrogacy and Organs*

The waiting lists for donations of oocytes and kidneys and the number of childless people show no signs of declining—on the contrary. At the same time, the options for sourcing commercial providers of eggs, surrogacy and kidneys in other countries are constantly im-

proving. In Denmark and the rest of Europe the legislation is geared to our view that it is wrong to trade in body parts; private citizens therefore have to travel to other, generally poorer countries if they wish to buy oocytes or kidneys, or 'rent' a womb. That poses a challenge to the national legislators, as they find it difficult to monitor or, where called for, even punish their citizens' actions if they take place outside of national borders.

As a rule this medical tourism involves the exploitation of weak individuals, e.g. desperately impoverished people press-ganged into selling their body parts for a pittance. This gives rise to a number of dilemmas, however, as the people buying the body parts themselves are not only in a very unhappy situation from which they see no other way out, but the 'donor' often perceives the sale of the body part as his or her best alternative, given their abject poverty.

Three examples of medical tourism

The Council has chosen to work on three examples of medical or health tourism, which differ in respect of ethically significant parameters and thus raise different ethical dilemmas.

The sale of unfertilized eggs and surrogacy does not necessarily place the donor in a physically worse state after the sale. Some countries permit the sale of oocytes and allow surrogate motherhood to be undertaken in return for payment, so to an extent it takes place in an open and controllable fashion.

It is different with organ trading, where a kidney donor is often physically much worse off after an operation. This is particularly due to organ trading, which is banned throughout the world, taking place illegally (trafficking) under extremely suboptimal conditions and generally without the requisite aftercare. There are also widespread accounts of donors being lured with false promises and not receiving the promised payment.

Such differences raise the question of what makes the commercialization of body parts ethically problematic, and whether all forms of body part sales are equally problematic. In the report the Council therefore takes a stance on the questions: Should the differences mentioned prompt us to graduate our view of the commercialization of body parts? Will it in some cases be possible to weigh up the commercialization issues against the relief provided by paying for such a service and, despite everything, afforded to people living in abject poverty, who regard the sale as the best option for improving their plight? And will it even be possible to set out criteria as to when the sale of body parts should be permitted, and when not?

A unanimous Council has endorsed the overall view that, in principle, the human body and its parts should not be able to be bought or sold. The rationale for this varies: people's dignity is violated by treating them as commodities, trading in body parts undermines the altruistic principle on which donation in the Danish health system rests, and trading in eggs in particular leads to a ranking of people. Finally, trading in body parts involves a considerable element of exploitation of the poorest people on the planet. The donors are not in

Debate day on medical tourism

The Danish Council of Ethics presented its report at a sell-out debating event held at Christiansborg, the home of the Danish Parliament, in December 2013. The Council had invited a number of speakers to the debate day, including the Canadian film producer Ric Esther Bienstock, who showed clips from her documentary film, *Tales from the Organ Trade*. All presentations were videoed and can be viewed on the Council's homepage.

> [Watch videos \(in Danish\)](#)



At a sell-out debating event in the Communal Hall at Christiansborg in December 2013 the Council presented its recommendations on trading in human eggs, surrogacy and organs.

a position to make a genuinely autonomous choice to sell their body parts.

Bearing this in mind, the majority of the Council's members consider that trading in body parts should be prevented.

For pragmatic reasons, however, a minority on the Council prefer a certification scheme under which, as a makeshift solution, sales can take place under controlled conditions to afford sellers the best protection possible.



Compensation for egg donation

STATEMENT On 1 February 2013 the Council published a statement about the compensation egg donors should be entitled to receive

“The Danish Council of Ethics endorses the wording of legislation that human eggs must not be made the subject of sales, based on a desire to avoid these possible consequences of commercialization.”

Thus reads the statement on compensation for egg donation, as published by the Council of Ethics in February 2013. By the same token, the Council acknowledges that compensation should be given to women donating eggs to childless people. However, the members disagree as to how much compensation should be granted:

- Reimbursement should be paid solely for transport costs and lost

earnings, so that in principle the same terms apply as for sperm donation, some members think.

- The egg donor should have her actual expenses reimbursed, and in addition can receive token recognition for her efforts, other members think. However, they consider that such symbolic recognition of the woman's efforts should not be so attractive as itself to motivate some women to enlist as egg donors. It must be on a par with sperm donation, though to some extent it may reflect the fact that harvesting eggs is a more invasive intervention than sperm donation; so, for instance, doubling the amount given for sperm donation might be an option.
- Greater compensation should be given for egg donation, though not so large as to endow it with the nature of actual payment for the donation, the remaining members feel. They thus stress acknowledgement of the great effort which the woman actually contributes to help those women and couples who experience infertility as an existential problem. These members have different views as to where the limit for compensation should be, suggesting amounts between a few and several thousand kroner.

The statement formed part of the Council's work on the report International Trade in Human Eggs, Surrogacy and Organs.



Potassium injection in the case of late abortion

STATEMENT The Danish Council of Ethics is divided on the question of injecting potassium chloride in connection with late abortion

The Council of Ethics published a statement in 2013 on the use of potassium chloride injection in connection with late abortion.

Potassium chloride injection can be utilized if it is wished to ensure that late-aborted fetuses/infants show no signs of life after birth.

When women terminate a pregnancy at the end of the second trimester, the fetus/infant is alive after the birth in an estimated 5-10% of cases and may show distinct signs of life. There has been discussion in the press and elsewhere as to whether doctors should be able to spare the woman/parents this experience. In some instances

women at some Danish hospitals are given the option of having potassium chloride injected, terminating the life of the fetus/child immediately prior to the abortion. The Council of Ethics has reviewed whether such a practice is ethically acceptable.

The Council's members are split into three different camps, reflecting different views of the interests involved:

- Some members of the Council of Ethics recommend “that potassium injection not be used in conjunction with permission for late abortion in Denmark, as the health service's task should be to save human life”.
- Some members recommend “that, by way of exception, women can be offered potassium injection if advocated by special circumstances – as regards the situation of the fetus/child or woman. The offer of potassium injection should be given based on the judgement of the healthcare staff in the individual situation.”
- One member recommends “that all women due to have a termination performed in week 20 of the pregnancy or later be advised on the scope for using potassium injection”.

Selected consultation replies

Insight into and use of data in the Danish health service

In 2013 the Council replied to a series of consultations dealing with insight into and use of the data generated during patients' encounter with the Danish health service.

The Council of Ethics' consultation replies have consistently rested on the principle that maintaining a confidential space to which citizens can come with their health-related concerns is a cornerstone of the Danish health service.

Providing access to that confidential space through legislation requires careful deliberation, assigning high priority to ethical values like confidentiality and the right to privacy, which have traditionally been mainstays of the Danish health service. The purpose of health professionals' duty of confidentiality is to safeguard trust in the fact that patients can consult the Danish health service and be met with confidentiality.

In its consultation replies the Council has recommended that access to patient data continue to be the subject of careful scrutiny, as safeguarding privacy is of great importance and value, both for the individual and for the working of the health service. Prioritizing values of a more organizational nature—like control, monitoring and rationalization—can break down this trust and the population's view of the Danish health service can change for the worse.

Opting out of life-prolonging treatment

Using both its own reports and previous statements and hearings, the Council has discussed ethical dilemmas associated with opting out of life-prolonging treatment, including resuscitation attempts, and with discontinuing treatment.

In 2013 the Danish Health and Medicines Authority (formerly the National Board of Health, Denmark) circulated a draft guideline on opting out of life-prolonging treatment, including resuscitation attempts, and on discontinuing treatment, outside of hospitals, for consultation. Among other things the guideline is based on previous discussions about mounting defibrillators in many public institutions, including care homes etc.

In its consultation reply the Council states that the draft guideline contains a number of positive aspects which are instrumental in clarifying citizens' rights as well as the professionals' responsibility and accountability. In the Council's opinion, however, the draft provides only a modicum of usable instructions in terms of how specialist nursing staff are to handle the hands-on dilemmas with which they are presented in their day-to-day work.

The Council is aware that it is not always possible to make clear-cut rules that eliminate the need for judgement calls. The Council emphasizes the importance of creating space for ethical reflection among this staff group so as to develop a good framework for evolving an ethically defensible practice for handling the ethical dilemmas involved in using defibrillators at care homes etc. Consequently, rules in the form of guidelines and so on should not detract the focus from the ethical dilemmas in which such professionals will find themselves in any event, any review of which requires ethical reflection.



In or out? About ethics and mental illness

TEACHING When a person is stricken with mental illness, the relationship with friends and classmates often becomes very difficult. The Council wished to focus on relations and get young people thinking about how they each individually can include mentally vulnerable friends and classmates, and it therefore published a set of material in 2013 for the eldest elementary school forms, paving the way for a debate on how young people manage mental illness

The debate material is called “In or out? About ethics and mental illness” and deals with acknowledging and respecting one another. Anyone affected by mental illness can experience isolation and loneliness – and their friends often find it hard to figure out how to

The Ethical Forum for Young People

The Ethical Forum for Young People first appeared in 2001, and in 2013 the Council published its seventh Ethical Forum for Young People – for the first time in purely electronic form with embedded video interviews. The Ethical Forum for Young People will appear again in 2015 on the topic of assisted reproduction.

react. The new material will arm pupils with fresh knowledge, challenging them to discuss dilemmas, e.g. about having regard for confidentiality issues or speaking openly about the illness.

Edith Mark, Chair of the Council's working party which compiled the material, explains:

“The ability to engage in social relations is altogether central to development and well-being, and particularly in one's early years it is good to be part of a community with one's peers. However, mental illness can be perceived as a barrier to entering social settings – for one thing it is painful for a young person with mental issues and, for another, relating to a friend with mental issues is challenging for many young people. The Council would like to help make it easier to understand and include young people with mental issues, so that no one is left out in the cold”.

In the material, young people who have experience of mental illness themselves at first hand during their early years tell of their own experience of engaging in social relations.



Climate-friendly energy source or food thief?

TEACHING In the wake of the Danish Council of Ethics' report on bioenergy, food and ethics from 2012, 2013 saw the Council launch new teaching material on bioenergy for upper secondary and elementary schools alike

In the media, bioenergy is alternately hailed as a climate-friendly, alternative form of energy and referred to as an unethical form of energy that converts “food for people” into “food for cars”. Both descriptions may be true, as there are many types of bioenergy with a very different impact on the climate and on the consumption of land for cultivation. The Council’s teaching material examines what is known as first-generation biofuels and second-generation technologies in existence or undergoing development, with their mutually different carbon footprints and land consumption.

In the debate on bioenergy, ethics plays a large – yet implicit – role. The Council's teaching material examines the ethical considerations that clash when it comes to deciding whether bioenergy is sustainable: regard for the climate, the environment, Danes alive now and future generations, and regard for the poorest people of the world.

Bioenergy versus climate change

The ice is melting, the oceans are rising and flooding low-lying areas, desertification is spreading and destroying the potential for farming. We are already seeing the effects of climate change in some parts of the world, but provisionally Denmark remains unaffected. On the other hand, it is being impacted by periods of extreme weather, violent rains and storms, which are also consequences of the globe's changing climate.

Right now climate change is damaging living conditions for people in exposed regions, for future generations and to some extent for ourselves too. Obviously, therefore, something needs to be done about the emissions of greenhouse gases which are causing global warming.

Bioenergy can act as a substitute for the fossil fuels which are the prime cause of climate change. But cultivating bioenergy crops competes with food production for scarce resources like land and water. Nowadays those types of bioenergy based directly on food crops are the most competitive, economically. The same applies to many types of imported biomass, which may very well have been produced to the detriment of food production or by cutting down forest to make room to grow the crops. In that case their climatic impact is small or may be decidedly negative, because when forests are felled, a lot of greenhouse gases are released.

The types with a positive climatic impact can be second-generation technologies based on those parts of the plant not suitable for food,

or on agricultural or domestic waste. But there are also non-edible energy crops, e.g. poplar, which have a beneficial effect on the climate if used as a substitute for fossil fuels. Commercially, however, these types are typically not profitable in the short term.

Climate-friendly bioenergy crops also monopolize areas of land, of course, but we use land for many other purposes which are easier to dispense with than energy; meat production, for example, requires large areas for cultivating forage.

Bioenergy is an ethical choice

The choice of bioenergy types is an ethical choice in the sense that choosing those types that yield a financial profit in the immediate term downgrades considerations of food production and possibly also of the climate. To do so is to take the narrow option of considering the interests which those who are alive have in cheap energy, to the detriment of people who live far away or have not yet been born, and at the expense of living conditions for species and ecosystems damaged by such climate change.

The background of the slide is a warm, orange-toned collage. In the upper left, there is a white icon of a fuel pump. To its right, a portion of a speedometer is visible, showing markings for 1/1, 3/4, 1/2, 1/4, and 0. A large, semi-transparent yin-yang symbol is centered in the background. On the left side, there are blurred images of yellow flowers. A purple rectangular box at the bottom contains the text.

Ethics in teaching

The topic of bioenergy is well-suited to interdisciplinary teaching in the eldest classes of elementary school as well as at secondary-school and higher-preparatory level in the subjects of biology, geography, social studies, religion and philosophy. The other topics on Ethics and the Building Blocks of Life concern the subjects: cloning, human genetic engineering, GMO, stem cell research, stem cell meat and human-animal chimeras.



Genome tests – what the genes are hiding

TEACHING With a set of teaching material on genome testing, pupils in Denmark in 2013 were given a foundation for understanding and debating the ethical dilemmas raised by the use of the latest genetic diagnostic techniques and the technical background to this

Genomes are now being mapped as never before, and in the years ahead technology is expected to improve hospitals' diagnosis of patients with signs of hereditary disease. By being able to search the patient's entire genome, there will be better chances of finding the cause of hereditary disorders in patients who have previously had to live in uncertainty.

What is a genome test?

A genome test is a form of genetic testing in which large parts of patients' gene pool or genome are examined at one time. The price of genome tests has plummeted since the first human genome was mapped in 2003, as a result of which many more people will be genome-tested in future.

Uncertain knowledge of risk?

Yet at the same time a series of mutations will invariably be found whose significance for future disease is uncertain. It is well known that misleading results can engender unfounded fears – or a false sense of security. When should doctors inform the patients about these? When should researchers report such information back to the trial subjects? And who is supposed to decide this? Should parents be able to genome-test their children at birth?

These questions also arise for the growing number of normal healthy citizens who, on their own initiative, are seeking access to information about their genetic risk factors. The fall in the price of genome tests has caused a number of private companies to offer genome tests to ordinary people. But – even for specialists – it can be extraordinarily difficult to evaluate the real-term health implications of such information.

The topic of genome testing lends itself well to interdisciplinary teaching in elementary school's eldest classes, and at secondary-school and higher-preparatory level in the subjects of biology, social studies, religion and philosophy.

Ethics on the school timetable

Project competition on ethics, bioenergy and genome testing

TEACHING In the autumn of 2013 the Council mounted a project competition and invited 9th and 10th forms from the whole of Denmark to reflect on ethical questions on either of the topics of bioenergy or genome testing

The pupils were able to choose between two interdisciplinary assignments and were encouraged to bring multiple media into their replies, e.g. writing, sound, film, collage, project description etc.

The prize for the class with the best answer was the opportunity to meet and discuss their project with Danish MPs and members of the Council of Ethics at an event held at Christiansborg on 28 November 2013.

New topics on Ethics and the Building Blocks of Life

Bioenergy and genome testing are the most recent topics on the Council's teaching site Ethics and the Building Blocks of Life. The site is frequently used by pupils from the eldest classes of elementary school and upper secondary school students working on interdisciplinary projects about the smallest building blocks of life, cells and their genes.

Pupils from Utterslev School won a day at 'Borgen'

Elementary school pupils all over the country sent projects in to the Council and their creativity was boundless: a silent film, news bulletins and a self-composed rap song were among the offerings submitted. The vice-chair of the Council, Ester Larsen, was really pleased, therefore, to see that the elementary school pupils had also proved capable of formulating their views on complex ethical problems:

"The young people's ability to adopt a stance on thorny, topical issues should definitely not be underestimated," says Ester Larsen, concluding optimistically: "If future politicians take the world's ethical problems equally as seriously as Utterslev School, I'm confident about the future."

The winning school was Utterslev School, which had collaborated across the 7th, 8th and 9th forms with assignments about genome testing, and with the help of many creative answers they had articulated their views on several of the ethical dilemmas raised by genome testing.

Genome tests viewed in a positive light

In their project Ipeka and Sylvester from Utterslev School's 7th form reached the conclusion that the pupils took a more positive view of



genome testing than their parents. We had an opportunity to ask Ipeka and Sylvester how they had worked on the ethical dilemmas raised by genome testing and what they thought about presenting the project to MPs and members of the Council of Ethics.

Ethics on the school timetable

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Activities in 2013

Overview of the Council's activities in 2013: Publications, consultation replies, organized events etc.

Publications

In 2013 the Danish Council of Ethics published a report, an anthology and a themed section on the Council's homepage:

- International trade in human eggs, surrogacy and organs
- Ethics and priority-setting in the Danish health service – why it's so difficult
- Themed section on euthanasia

Statements

In 2013 the Council of Ethics published two statements:

- Use of potassium injection for late abortions in the Danish health service
- Statement on compensation for egg donation

Consultation replies

The Council of Ethics provided replies to 15 consultations in 2013:

- Draft bill to amend the Danish Health Act, Act on the Right of Appeal and Compensation within the Health Service, and Act on Authorization of Healthcare Professionals and Healthcare Activities
- Draft guideline on opting out of life-prolonging treatment, including resuscitation attempts, and on discontinuation of treatment, outside of hospitals
- Draft bill to improve support for the childhood vaccination programme etc.

- Draft bill to amend the Health Act and Act on the Right of Appeal and Compensation within the Health Service (equality between psychiatric and somatic patients in terms of free choice of hospitals, right to speedy investigation within the hospital service and the differentiated right to extended free choice of hospitals)
- Draft bill to amend the Civil Registration System Act (allocation of a new social security number in special cases and abolition of records in the Civil Registration System (CPR) regarding protection from researchers' enquiries)
- Draft executive order on medication and vaccination data
- Draft amendment to executive order on information and consent to participate in health science research projects, and on registration and supervision of health-science research projects
- Draft bill to amend the Act on Assisted Reproduction in connection with Medical Treatment, Diagnosis and Research etc. and Act to amend the Act on Requirements for Quality and Safety in the Handling of Human Tissues and Cells (The Tissue Act) and the Children's Act etc.
- Draft executive order on nationwide and regional clinical quality databases
- Draft bill etc. to implement the Patient Mobility Directive
- Draft amending order concerning assisted reproduction
- Draft bill to amend the Health Act, and Act on the Right of Appeal and Compensation within the Danish Health Service
- Draft report with proposals to regulate collaboration between healthcare staff and drug and medical device manufacturing companies
- Draft bill to amend the Children's Act and various other laws (co-motherhood etc.)

- Draft bill to amend the Health Act and Tissue Act (adjustment relating to right of access, living donors' consent for donation, sterilization and qualification of the definition of adverse drug reactions when handling human tissues and cells etc.)

Debating events

The Council of Ethics held two large debating events in 2013.

Dec. 2013	International trade in human eggs, surrogacy and organs. Presentation of the Council's report at the debating event held in the Communal Hall at Christiansborg, 18 December 2013.
April 2013	Ethics and priority-setting in the Danish health service – why it's so difficult. Presentation of an anthology at the debating event at Vejle Hospital, 15 April 2013.

Council meetings

The Council of Ethics held 11 ordinary council meetings in 2013:

Dec. 2013	Council meeting 283
Nov. 2013	Council meeting 282
Oct. 2013	Council meeting 281
Sept. 2013	Council meeting 280

Council members' public speaking engagements

2013 saw various members of the Council take part in more than 100 debating events all over Denmark, organized by e.g. universities, hospitals, extramural departments, lecture societies, special-interest associations, colleges, parish councils etc.

Aug. 2013	Council meeting 279
June 2013	Council meeting 278
May 2013	Council meeting 277 (residential meeting)
April 2013	Council meeting 276
March 2013	Council meeting 275
Feb. 2013	Council meeting 274
Jan. 2013	Council meeting 273

Teaching

In 2013 the Council of Ethics published new teaching topics for elementary and upper secondary schools and staged a project competition for elementary schools:

- Ethics on the school timetable. Project competition for eldest classes of elementary school on ethics, bioenergy and genome testing.
- The Ethical Forum for Young People 2013: In or out? About ethics and mental illness
- Ethics and the Building Blocks of Life: Bioenergy – climate-friendly energy source or food thief?
- Ethics and the Building Blocks of Life: Genome testing – what the genes are hiding

Council members, 2013



The Council's work in 2014-2015

In 2014 the Council of Ethics set up a number of new working parties, which are expected to end during 2014 and 2015

Use of diagnoses

The Council's work on this topic is based on a trend in society towards an increase in diagnostic categories and a perception that diagnoses are increasingly being used outside of the purely specialist medical domain.

The aim of the work is to identify the ethical problems and dilemmas linked to the different relations in which clinical diagnoses are used, for example between patient and GP or between citizen and health authorities.

Being given a diagnosis can be “the best thing” and “the worst thing” for a person. Taking ethics as its focus, the Council has an opportunity to discuss aspects such as what disease actually is and what consequences a diagnosis has for the individual's identity and interaction with others.

Research in health data and biobanks

Developments in IT and biotechnology have made huge volumes of information about citizens' health accessible for research and analysis. By analyzing and comparing data from biobanks and data registers, highly precise information can now be obtained about causes of disease and the effect of different forms of treatment on particular groups or individuals, for the benefit of patients and the national economy in the short and long term.

At the same time, however, this development is putting traditional regard for trial subjects and patients under pressure. What does it

mean for the individual that far more personal data about the individual citizen are being stored? How are society's wishes for more effective research being balanced with the individual's requirement for self-determination? The ethical dilemmas that have historically characterized human health research are being raised with renewed vigour in current years.

Sustainable food

Climate change is perhaps the key ethical question which present generations are having to relate to. The phenomenon affects us all, albeit only to a slight extent for the moment, but global warming and its consequences are progressing far faster than hitherto predicted, and in terms of halting that warming before such changes become irreversible there is a 'window' of very few years. In the same way, degradation of the environment and biodiversity, and overconsumption of non-renewable natural resources pose a threat to posterity.

Is it up to the individual Danish consumer to ensure that our collective food consumption is sustainable? Should farming and retail outlets take some responsibility too? Or should the politicians legislate and thus make sustainable consumption a collective responsibility? And if so, in which instances is it appropriate to legislate?

With its track record of generating debate, the Council wishes to stimulate discussion as to when ethically justified initiatives are appropriate in the area of food, and whether and in which instances labelling is the best option in terms of regulation.

Ethical Forum for Young People, 2015

The application of new technology raises a plethora of ethical questions about having children. That will be the main topic of the Ethical Forum for Young People in 2015.

Possible discussions rooted in the material can deal with assisted reproduction, the right to know one's parents, fetal diagnosis or "de-

signer children". Using means including workshops with pupils from 9th classes, the Council will develop the form and content of the material.

Neuroethics

During deep brain stimulation an electrode is implanted in the brain and acts on a specific area using electrical stimulation. The technique is used with Parkinson's disease, among others. Within a number of years other related technologies are expected to be developed, also aimed at influencing the brain directly. During 2014, therefore, the Council will create a themed page on the subject on its website. Initially, the themed page will contain a statement from the Council of Ethics on deep brain stimulation, a short story by Svend Åge Madsen, and texts about neuroethics and science fiction. In the longer term the plan is to expand the themed page as and when more neurotechnologies are developed.

Questions about assisted reproduction

In the course of 2014 the Danish Council of Ethics plans to make two statements on the subject of assisted reproduction. The subject of the first statement is the ethical dilemmas raised in connection with embryo and double donation. In the case of embryo donation a couple who have an embryo (fertilized egg) left over from assisted reproduction donate it to a woman or a couple; it is then implanted into the woman's uterus with the aim of her becoming pregnant and giving birth to the child. In the case of double donation a woman or a couple receive both eggs and sperm from donors.

The subject of the second statement will be selected in autumn 2014.



About the Council of Ethics

The Danish Council of Ethics was set up in 1987, its task being to advise Danish Parliament and public authorities as well as to generate debate among the public on new bio- and genetic technologies affecting people's lives, the countryside, the environment and food. In addition the Council is engaged on ethical questions otherwise connected with the Danish health service.

The Council is an independent council, meaning that it is autonomous and cannot take instructions or similar briefs from either ministries, Danish Parliament or others with regard to which tasks to accept.

The Council consists of 17 members appointed for a three-year period with the option of reappointment once. Council members are unpaid.

The Danish Minister of Health and Prevention officially appoints the Council's members. When designating and appointing members, it must be ensured that both laypersons and specialists are represented, and that there is only one more of either sex than the other.



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