



THE DANISH
COUNCIL OF
ETHICS



Annual Report 2014

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Preface

In January 2014, 10 new members were appointed to the Danish Council of Ethics to join the Council's total of 17 members, and in February the Council held a seminar to plan the work schedule for the next year.

The following three working groups were adopted:

RESEARCH ON HEALTH DATA AND BIOBANKS Advances within IT and biotechnology have made large volumes of public health data available to research. By analysing and comparing information from biobanks and data registers, it is now possible to obtain highly accurate information about causes of diseases, effects of various treatment forms in certain populations or individuals for the benefit of patients and national economy in the short and long term.

It is a development that puts traditional regard for research participants and patients under pressure. What does it mean to the individual that increasing volumes of personal information are being stored about him or her? How do we balance society's wishes for effective research with the individual's right of self-determination? The ethical dilemmas that have historically characterised health research are these days being raised with renewed vigour.

USE OF DIAGNOSES The Council's work with this theme has been based on a societal trend of increasing diagnostic categories and the perception that diagnoses are increasingly being used outside the purely medical sphere.

The aim of this work has been to uncover the ethical problems and dilemmas associated with the different relationships in which diagnoses

play a key role, e.g. between patient and general practitioner or between citizens and health authorities.

Being diagnosed with a disease can be "the best" or "the worst" thing can happen to a person. With the ethical element in focus, the Council was able to discuss aspects such as what disease really is and what consequences a diagnosis will have for the individual's identity and interaction with other people.

THE ETHICAL CONSUMER Climate changes are perhaps the most important ethical question that today's generations will need to consider. This phenomenon concerns us all, and although we are not impacted heavily yet, global warming and its implications are much faster than predicted so far, and the "window" through which to stop warming before changes are irreversible has narrowed considerably in only a few years. Similarly, the depletion of the environment and biodiversity as well as excess consumption of non-renewable natural resources are a threat to future generations.

Should each Danish consumer be responsible for ensuring that our collective food consumption is sustainable? Should the agricultural sector and the retail outlets assume responsibility too? Or should the politicians make sustainable consumption a joint responsibility via legislative means? And if so, in what cases would legislation be appropriate?

The results of the working groups are expected to be announced during 2015.

The Council furthermore published three statements on the "Use of antibiotics", "Embryo/double donation" and "Deep brain stimulation", all of which themes that present contrasting ethical dilemmas.

In its statement on deep brain stimulation, the Council chose an untraditional informative approach by publishing a digital work under the title "Neuroethics" with contributions by e.g. Danish author Svend

Åge Madsen who has written a short story "Hin Anden" (Each Other), which is a brilliant example of how successful story-telling can spur the debate by imagining how future use of brain technology can affect the individual's identity and thus also our human communities. The short story, which is in Danish only, is found in the annual report.

Like the year before, the Council focused on preparing and updating teaching material for upper secondary and elementary schools via the Council's educational websites "Ethics and the Building Blocks of Life" and "Ethical Forum for Young People", accessible via the Council's main website www.etiskraad.dk.

The Council's key tasks are to generate debate and give advice to Danish Parliament. The debate-generating activities require the Council to be capable of reaching out to a number of different target groups: Children and the young, experts, politicians and the individual citizen. During 2014, the Council members participated in more than 100 national debating events organised by universities, hospitals, lecture societies, university extensions, hospices, local church councils, colleges, etc. The Council also participated in the people and politicians meeting known as "Folkemødet" on Bornholm and hosted several debating events over the course of the year.

You can read more about all these activities in this annual report.

Enjoy the read!

Jacob Birkler
Chairman

Christa Kjøller
Director of Secretariat

2014 in numbers



2014 in numbers **230.000** visits and more than **500.000** page views on the Council's website.

500
+500
1000

The Danish Council of Ethics received more than **1,000** enquiries from more than **500** citizens and about **500** students and thus advised and provided information for use in projects and school assignments using the teaching material from its website and other information.



The Danish Council of Ethics held **11** meetings, one of which was a residential seminar.

11

The Danish Council of Ethics received **25** consultations.



The Council's website is updated with the statements and consultations that the Council worked with in 2014. Publications have been uploaded as well as a series of video clips from past debating events. In addition, we have created a new theme page about health data to follow up on the theme day dedicated to research on health information.



75 per cent

of our users visit etiskraad.dk via Google.



>
20
pct.

More than **20 per cent** of our users visit our website etiskraad.dk from a mobile device (up from 15 per cent in 2013).

The content visited the most on our website is¹:

- What is ethics?
(Ethics and the Building Blocks of Life)
- Information about the Council and its members
- Theme about euthanasia
- Texts about cell biology
(Ethics and the Building Blocks of Life)
- Theme about GMO
(Ethics and the Building Blocks of Life)
- The Council's publications



We launched our Twitter profile in 2014.

Follow us on: twitter.com/etiskraad



2000

In 2014, the Council's newsletter reached 2,000 subscribers. Our newsletter is in Danish and keeps subscribers updated with the work of the Council. Follow this link to subscribe:

etiskraad.dk/nyhedsbrev

¹ The content visited the most is on our Danish website.



Avoid using antibiotics "to be on the safe side"

STATEMENT In January 2014, the Danish Council of Ethics published its unanimous statement on antibiotics, recommending to avoid using antibiotics "to be on the safe side" or to reduce discomfort. The Council wishes to facilitate and quality societal decisions on how to mitigate the growing threat of antibiotic resistance.

In the opinion of the Council, the resistance problem cannot alone be solved by stopping irresponsible antibiotic use. Even sound and appropriate use of antibiotics promotes resistance development. Prescription restraints are therefore advised even if it involves a small risk for patients, animals and livestock. In other words, solutions to fight antibiotic resistance raise dilemmas that must be acknowledge by authorities, doctors and veterinarians as well as patients and consumers.

Cutting down antibiotic use is a dilemma

Gorm Greisen, Chairman of the Council's working group that has looked closer at the ethical dilemmas associated with the resistance problem, says:

”If we want to make sure that patients in the future have the same possibilities of being treated for infections as today’s patients, we will need to look at whether some of the patients and animals that are given antibiotic treatment today ought not to have it in future. We don’t believe it can be done with significant impact without exposing patients and animals to a risk. If we cut antibiotic use, doctors, veterinarians and farmers are put in a dilemma, and this is something society must acknowledge. We cannot ask them to cut down on antibiotics without being open about it”.

On the Council’s website you can read the statement and the three underlying working papers (in Danish only). The working papers address ethical aspects, medical and veterinary aspects as well as social aspects of the resistance problem and have contributed significantly to the investigative work on which the statement is based.

[Read the statement >>](#)



INTERVIEW *Should doctors prescribe antibiotics ”to be on the safe side” or to reduce discomfort? Watch this interview (in Danish only) with doctor Michael Dupont and kidney patient Malene Madsen who discuss the inherent dilemmas of having to balance the treatment needs of present and future patients. Is it, for example, reasonable to prescribe antibiotics for aesthetic conditions like acne knowing that such use will reduce future patients’ access to effective and perhaps even life-essential antibiotics?*



Embryo and double donation – new techniques in assisted reproduction

STATEMENT In embryo donation, a woman donates a surplus fertilised egg from fertility treatment to another woman or a couple. In double donation, both egg and sperm are donated, which could come from a woman and a man who neither know each other nor the recipient. The egg is then fertilised outside the body. In both methods, the fertilised egg is inserted into the future mother who will then experience pregnancy and give birth to a child to whom she has no genetic relation.

Embryo and double donation are techniques which are not allowed in Denmark today. This is because Danish legislation stipulates that at least one of the future parents must be genetically related to the child, which is not the case in either embryo or double donation.

The Danish Council of Ethics issued a statement about this in the summer of 2014 in which a large majority of the members recommended that the two forms of donation be legitimised. A minority did not want

to legitimise any of the two donation forms, and one member wanted to legitimise double donation only.

The statement discusses a series of arguments for legitimising or prohibiting embryo and double donation, e.g. the interests of the unborn child, the parents' right to decide themselves and the ethical status of the embryos, including whether legitimising embryo donation is compatible with treating embryos in a dignified manner.

The statement also presents a number of themes which the Council finds are necessary to address if the two forms of donation should become legal in Denmark. Among these themes is the question whether donations should be anonymous and whether any changes should be made to the provisions regulating the permitted storage time for embryos and egg cells.

[Read the statement >>](#)

What is embryo and double donation?

In embryo donation, a woman donates a surplus fertilised egg from fertility treatment to another woman or a couple. In double donation, both egg and sperm are donated following which the egg is fertilised outside the body. In both methods, the fertilised egg is inserted into the future mother who will then experience pregnancy and give birth to a child to whom she has no genetic relation.



The Danish Council of Ethics okays electrical impulses to the brain

STATEMENT In October 2014, the Danish Council of Ethics published a statement on Deep Brain Stimulation (DBS). The statement is part of the Council's theme publication on neuroethics.

DBS is a form of treatment that can be used in certain groups of seriously ill patients with, for example, Parkinson's disease, obsessive compulsive disorder or severe depression. In this treatment, the patient has a small electrode implanted into a specific area of the brain. By applying a small electrical impulse to an electrode, some of the patients' symptoms can be stopped. If the electrode is surgically removed, the symptoms are likely to return, but the treatment is assumed not to have a permanent effect on brain function. The treatment form is reversible in other words.

DBS has been used in Denmark since the late 90s primarily for the treatment of patients with Parkinson's disease, essential tremor (familial tremor) and dystonia (muscle spasms). It is also being considered whether to offer it to severely depressive patients on a trial basis.

In the statement, the Danish Council of Ethics concludes that "the ethical considerations related to using the technology are principally the same as those related to other treatments". However, the Council is also aware that the use of DBS involves a higher risk compared to many other treatment forms because it targets the brain, which is a highly complex structure. For this particular reason, it may be difficult to predict what unintended consequences DBS treatment might have. However, the Council finds that the way to tackle this problem is not to avoid using the treatment entirely. We should instead proceed cautiously and in the beginning only offer treatment to the patients who are severely afflicted for whom the more established treatment forms have already been tried. Obviously, it would be a requirement that the treatments have been approved via normal procedures regardless of whether any such treatment is on a trial basis or is a standard treatment offer.

The Danish Council of Ethics' main concern of using DBS is that the patient groups that could benefit from DBS are initially people who already find themselves in a difficult situation; Either because there are no other treatment options, or because the patients are so mentally afflicted by their disease that it would be difficult for them to comprehend and foresee the consequences of treatment. Therefore, the Council recommends that "independent advice be considered in trials involving DBS treatment due to problems specifically related to participation consent." Such advice could be offered by a doctor who is not involved in the research project or another independent person.

[Read the statement in Danish >>](#)

What is Deep Brain Stimulation?

Deep brain stimulation (DBS) is a treatment form for seriously ill patients. In DBS treatment, patients have a small electrode implanted into a specific area of the brain. When a small electrical impulse is applied to the electrode, many of the patients' symptoms stop. If the electrode is surgically removed, the symptoms are assumed to return.



A different way of working with ethical themes

THEME In order to contribute to a living debate on the ethical challenges of brain research, the Council has used unconventional methods to raise awareness with a digital publication about neuroethics.

The Council announced its publication about neuroethics in the autumn of 2014, and additional to the Council's statement on Deep Brain Stimulation, it features a piece of fiction, which has never been tried before.

Author Svend Åge Madsen has written a short story titled "Hin Anden" (Each Other) especially for the Danish Council of Ethics to put focus on the promising, yet frightening, perspectives that brain research carries with it. The short story is but one of several paths into the ethical considerations in modern brain research. Other paths include the Council's statement on Deep Brain Stimulation, critical comments on the statement and texts about how the science fiction genre can be used to enhance the ethical debate.

Commenting on the use of literature in the publication on neuroethics, Chairman of the working group, Mickey Gjerris says:

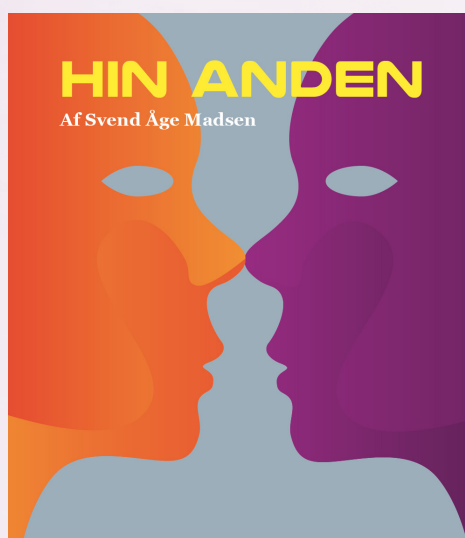
”Literature feeds our imagination. Fiction lets us unfold who we are in situations where we wouldn’t normally be. When we consider the future’s technological openings and the ethical problems that could arise, the science fiction genre is a brilliant medium through which we can form opinions about what we ethically think of the future possibilities.”

Svend Åge Madsen’s short story ”Hin Anden” is a brilliant example of how successful story-telling can spur the debate by imagining how future use of brain technology can affect the individual’s identity and thus also our human communities. Thus, the short story highlights in parallel what aspects of the human form of existence it may be necessary to preserve for the sake of community.

The intention is to regularly update the publication with descriptions of new technologies in the area and the ethical questions and dilemmas prompted by such new technologies.

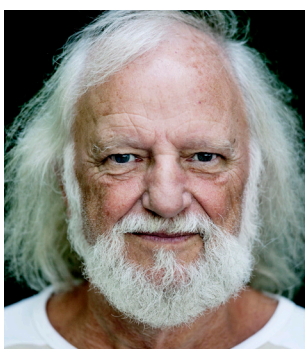
[Read the publication \(in Danish only\) >>](#)

[Read the short story, “Hin Anden” \(in Danish only\) >>](#)



Neuroethics

The Council's publication, Neuroethics, addresses the ethical challenges posed by new treatment forms which brain research paves the way for. With this publication, the Council presents an entirely new way of working with ethics by introducing fiction. Author Svend Åge Madsen has contributed with his short story "Hin Anden" (Each Other).



Svend Åge Madsen, born 1939

Svend Åge Madsen published his first novel "Besøget" (The visit) in 1963 and has since authored more than 30 novels, several collections of short stories and plays. He is especially known for his way of experimenting with language and his work with novel expression forms using e.g. hypertexts and SMS short stories. Throughout his career, he has received many of the major Danish literature prizes.





Updated teaching material on stem cell research and ethics

TEACHING Stem cells is a novel research area that has the potential of revolutionising therapeutic treatment. However, many people find that stem cell research poses ethical problems – especially because it uses stem cells from fertilised eggs. In the spring of 2014, the Council presented its updated teaching material for both elementary school and upper secondary school.

Stem cell research has advanced rapidly over the past years. New stem cell types have been discovered, and the possibility of reprogramming body cells to unspecialised cells similar to those found in fertilised eggs has turned out to be far greater than believed so far. Research turns upside down what we know about when life begins and how our cells, the body’s building blocks, can potentially be controlled and used in treatment of disease.

Ground-breaking research

In the eight years that have passed since the Council launched its teaching material about stem cells, research has made such giant leaps that we have now updated our educational web pages, Ethics

and the Building Blocks of Life, targeting both the eldest classes in elementary schools and upper secondary schools. We have integrated new revolutionary research from the University of Copenhagen so that pupils can learn how specialised connective tissue cells are being reprogrammed, corrected for disease genes and then specialised again – this time to neural cells that can be inserted in the patient’s brain to treat inherited brain diseases. This is ground-breaking research if it can be confirmed in controlled trials.

Ethical problems

Whether it is considered wrong to separate embryos depends on how people look at embryos and the value or status they consider them to have. In the material, the ethical key points are presented and challenged in a discussion between two ethicists.

Read the material on stem cells and ethics (in Danish only) >>



***POUL HYTTEL** is Professor at the University of Copenhagen and stem cell researcher. In this video, he talks about how you can take a skin sample from a patient with inherited dementia, reprogram the skin’s connective tissue cells to iPS cells – i.e. “rewind” them to a state similar to their early embryonic state – correct the iPS cells for the genetic defect and then edit them to specialised neural cells for re-injection in the patient’s brain.*



EthicsBattle, competition for upper secondary students on stem cells and ethics

TEACHING After publishing the new teaching material on stem cells, the Council launched a competition in the autumn of 2014 called EthicsBattle. The competition is held every year and is targeted at upper secondary schools.

In this year's project competition, upper secondary school students across Denmark were challenged to complete a number of assignments that required both insight into the scientific background of stem cells and the various ethical views in the area.

To enter the competition, the students had to answer and consider a series of questions specifically aimed at the subjects of biology and religion as well as inter-disciplinary sessions between the two subjects.

The participating upper secondary schools could choose between five main questions, all addressing stem cell research and ethics.

In their replies, the students could use texts, video clips and interviews from the Council's teaching material on stem cell research and ethics, and the replies could be presented as a scientific poster or a PowerPoint presentation designed in such a way that all main points of the reply were comprehensible without further explanation. The poster or presentation was then also to serve as the basis for an oral presentation that the groups were to hold in class.

The Council had formed an assessment committee consisting of Council members assisted by a gene researcher and a biology teacher. Ester Larsen, former Health Minister and Vice-chair of the Danish Council of Ethics, chaired the committee. The submitted replies were assessed against criteria stating that the replies should be thorough and competent, the scientific information presented should be interesting and serious, and the students should moreover be able to show that they had considered the ethical dilemmas and could defend their views.

Celebrating the winners at Christiansborg

Three winning classes were found among the submitted replies, and on 15 April 2015 the winners got the opportunity to present their projects to each other and a panel composed of experts, members of the Council and politicians.

In this video clip in Danish, you can hear how the students experienced participating in EthicsBattle:



A selection of the competition questions

- What are the prospects of resetting adult stem cells to totipotent stem cells?
- How does this differentiation take place? Do these particular new technical possibilities give rise to consider any special ethical problems?
- Discuss the ethical arguments for and against producing totipotent stem cells, and consider which arguments are strongest.

Try to compare the view on human nature as presented by the researchers (Mustapha Kassem, Ann Dorte Pørneki and Poul Hyttel) and bioethicists (Peter Øhrstrøm og Klemens Kappel). Are human beings special and, if so, how are the special?

Find three examples of specific stem cell treatments that are, or are close to, being used in the treatment of disease. Make up one or more future scenarios, and assess the ethical implications they may have. How far should science go?

The winners of EthicsBattle 2014-2015 were:

Bagsværd Boarding School and Upper
Secondary School, 4BT
Roskilde Upper Secondary School, 3a
Holstebro Upper Secondary School, 2y



Debating events in 2014

On 23 January 2014, the Council met with the Committee on the Danish Council of Ethics in the Danish Parliament to discuss the Council's work in 2014.

For the first time, the Council participated at the "Folkemødet" – the people and politicians meeting on Bornholm – from 12 to 14 June 2014. The Danish Council of Ethics teamed up with the Danish Medical Association, the Danish Veterinary Association and the Association of Danish Pharmacies to organise the debating event "Antibiotics are running out – what will you do?" with Gorm Greisen as the speaker. In addition, the Council members participated in a series of debating events/activities during the Folkemødet in collaboration with the Danish Health and Medicines Authority, the Danish Church, the online newspaper Altinget, etc.

As part of the Working Group on Research on Health Data and Biobanks, the Council held a symposium on 19 June 2014 about research on health data, which was followed up by a debating event on 11 December 2014 at Christiansborg, with participation by members of parliament, stakeholders, citizens, reporters, etc. There were altogether 200 participants.

[Watch video from the symposium >>](#)

On 11 August 2014, the chairmanship met with Minister for Health Nick Hækkerup to discuss the work of the Council.

As part of the Council's work with "Ethical Consumption", the Council co-organised a debating event on 17 November 2014 with the Danish Agriculture & Food Council under the heading: Is it the ethical consumer's responsibility to ensure climate-friendly food consumption?



The event was joined by 120 participants, and a total of 276 users followed our live streaming. An anthology with the contributions was sent out in January 2015 (in Danish only)

[Read the anthology >>](#)

Furthermore, the Council members participated in more than 100 national debating events organised by e.g. universities, hospitals, university extensions, lecture societies, stakeholder organisations, colleges, hospices and local church councils.

As part of the international collaboration, the Chairman of the Council participated in the World Congress of Bioethics from 24 to 27 June 2014 in Mexico.

The Chairman and the Director of Secretariat participated in the meeting with the National Ethics Committees (NEC)

Consultations in 2014

The Danish Council of Ethics received 25 consultations of which the following gave rise to elaborative responses:

24 October: Response to consultation on executive orders and guidelines on tissues and cells as well as assisted reproduction.

Read the response >>

29 August: Response to consultation on draft bill to amend the Act on Use of Coercion in Psychiatry.

Read the response >>

13 August: Response to consultation on Executive Order on Encoding and Data Capture in General Practice, Reporting of Data to the Region and Publication of Information about the Physician or Clinic.

Read the response >>

20 June: Response to consultation on draft guideline on examination and treatment of transgendered persons.

Read the response >>

28 March: Response to consultation on draft bill to amend the Civil Registration System Act (allocation of new civil registration number to persons who perceive themselves as belonging to the opposite gender).

Read the response >>

28 March: Response to consultation on bill to amend the Health Act and the Act on Assisted Reproduction in connection with Treatment, Diagnostics and Research, etc.

Read the response >>

Danish Council of Ethics

– tasks in 2015-2016

The three current working groups on "Diagnoses", "The Ethical Consumer" and "Research on Health Data and Biobanks" are expected to finish their work in 2015, which will be followed up by a range of activities and debating events.

In the spring of 2015, the Council published a statement on "Storing and use of unfertilised eggs", which, among other things, discusses *social freezing*. [Read the statement >>](#)

As current working groups finish their work, new working groups are formed. When the Council meets in June 2015, it will plan the themes for the next years.

However, it has already been decided that in the autumn of 2015, the Council will be working with the theme "Coercion in somatic treatment of children" in collaboration with the National Council for Children.

New teaching material will also be added to "Ethical Forum for Young People" and "Ethics and the Building Blocks of Life".



In the spring of 2015, the Council published an educational leaflet "Ønskebarn" (Love child) together with a website which addresses the choices to be made when children are brought into the world assisted by technology. Today, almost one in every ten children are born via artificial insemination, also called assisted reproduction. Modern medical science has given us more choices and made it more common to get help having children. Technology opens up new doors, and for many involuntary

childless people, it represents the needed help to fulfil their dreams of having children and a family. But with opportunity also comes several questions that we need to deal with. [Read *Ønskebarn \(Love child\)* >>](#)

In 2014, the Council launched the EthicsBattle competition in conjunction with a considerable update of the teaching material about stem cell research and ethics on the educational website "Ethics and the Building Blocks of Life". In April the competition culminated with a day at Christiansborg celebrating the winners.

In August 2015, the Council will be meeting with the Swedish National Council on Medical Ethics with the purpose of sharing experience and discussing current themes.

The Council will also be meeting with the Committee on the Danish Council of Ethics in the autumn to discuss a number of relevant themes, including the collaboration with the Committee, the results of the Council and the planning of the Council's 30th anniversary in 2017.

In addition, the Council will continue its debate obligation by participating in a line of debating events across Denmark, including the people and politicians meeting on Bornholm known as "Folkemødet".

In the autumn of 2015, the Council will reveal its new visual identity and new websites whose design will be more aimed at the Council's target groups and users than the case is today.

The year will be closed by the appointment of a new Chairman of the Council as our present Chairman is resigning in March 2016 after six years on the Council.

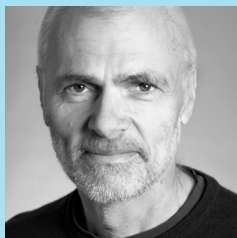
Members of the Danish Council of Ethics in 2014



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Chairman
MA, PhD
Associate Professor,
Teacher
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Mickey Gjerris
Master of Theology, PhD
Associate Professor
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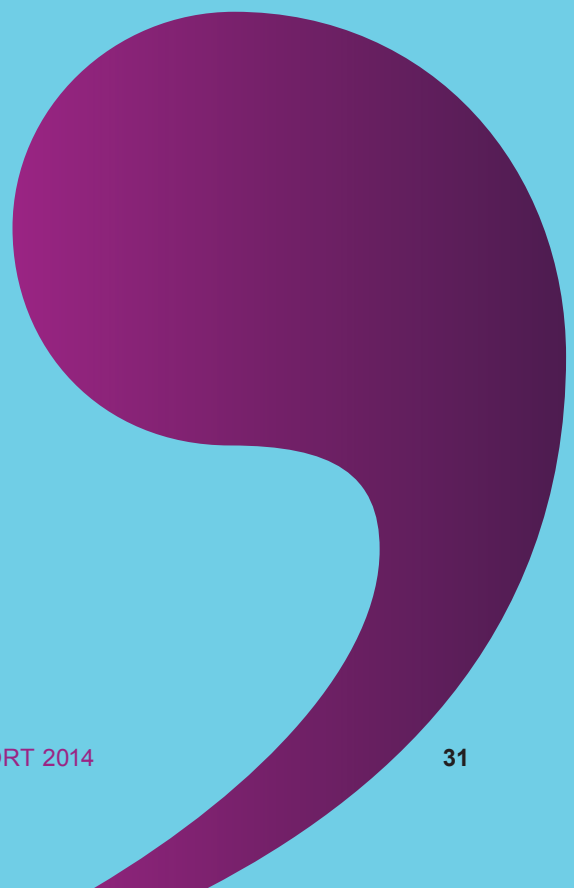
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Professor
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About the Council of Ethics

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 in 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 Ministers, 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 for Health 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.

Read more about the work of the Danish Council of Ethics at www.etiskraad.dk





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ETHICS

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