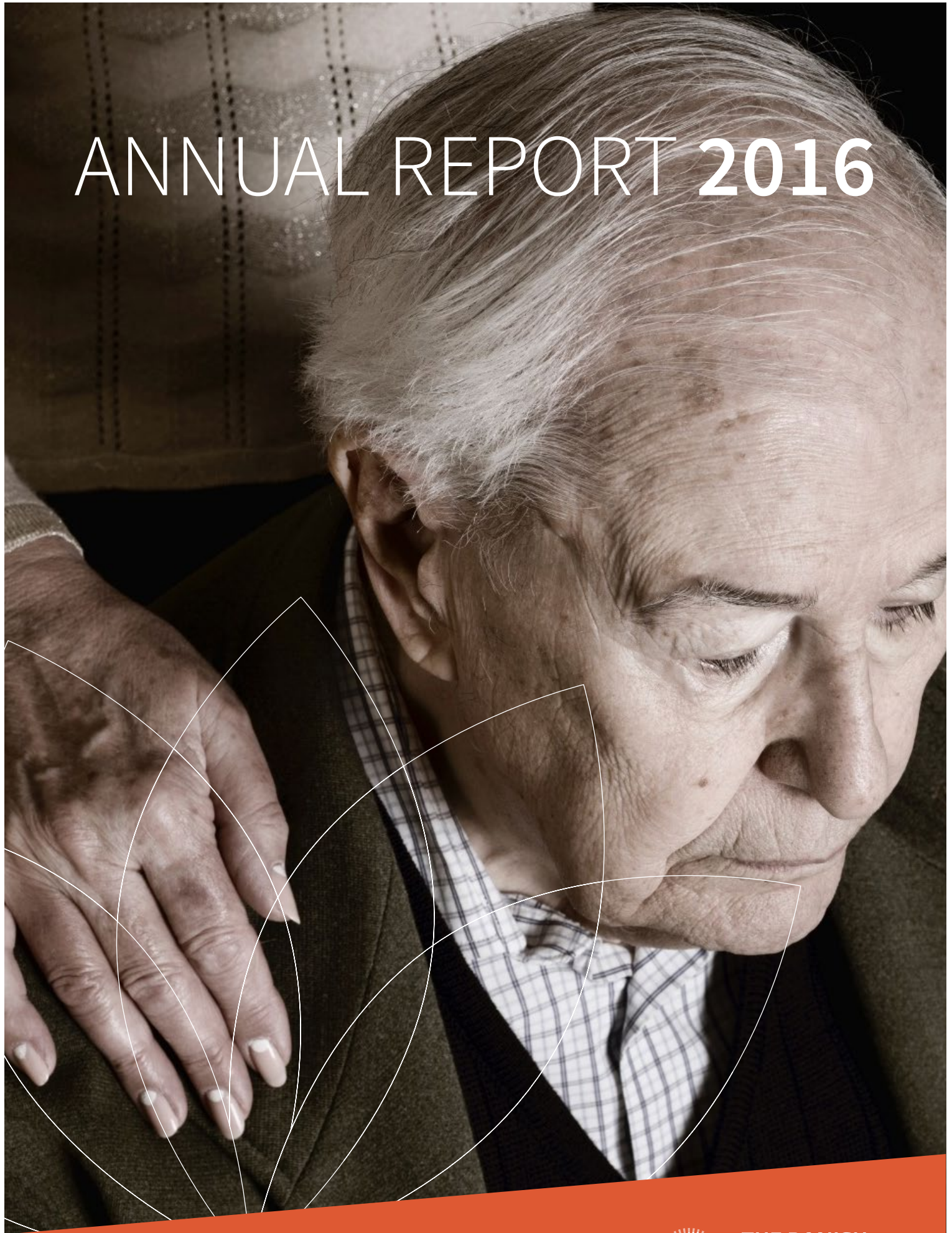


# ANNUAL REPORT 2016



THE DANISH  
COUNCIL  
ON ETHICS

## Annual Report 2016 of the Danish Council on Ethics

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Danish Council on Ethics  
[www.etiskraad.dk](http://www.etiskraad.dk)  
[kontakt@etiskraad.dk](mailto:kontakt@etiskraad.dk)

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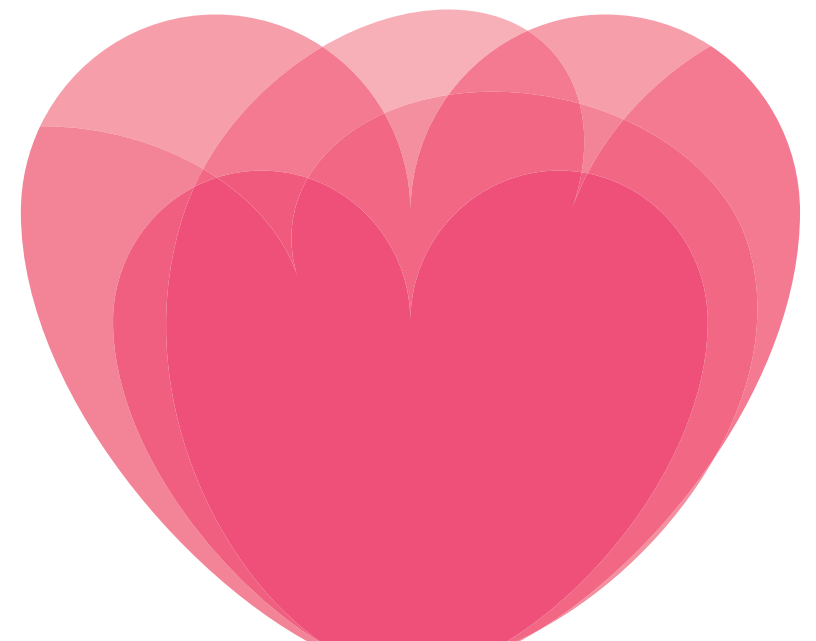
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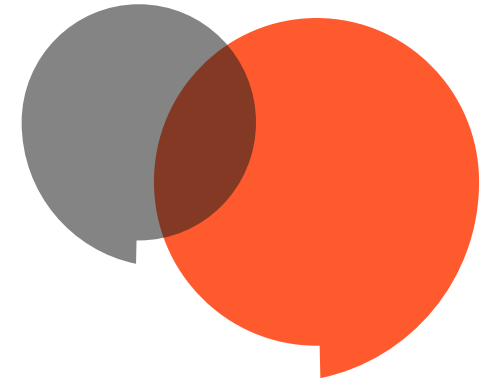
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# Preface



2016 was a busy year for the Danish Council on Ethics.

The year opened with the presentation of our work with [ethical issues in diagnosis](#). Being diagnosed with a disease could be "the best" or "the worst" thing happening to someone; best because it may give clarification, access to the right treatment and new opportunities; worst because the diagnosis can be stigmatising and tie the individual to an unwanted identity. The publication came after almost 18 months of work, where the Council provided a framework for dialogue between and among people with diagnoses, practitioners, relatives, experts, etc.

A new chairman of the Danish Council on Ethics, Consultant and Clinical Professor, Gorm Greisen, was elected in spring.

In the subsequent period, the Council announced its [recommendation to put a tax on beef](#) in effort to curb Danish meat consumption. On a global scale, food production accounts for between 19% to 29% of greenhouse house gas emissions, of which cattle alone account for 19% of emissions. The recommendation was published as part of the Council's work with the ethical consumer to raise awareness of the food area's massive impact on greenhouse gas emissions. The recommendations aroused debate at dinner tables across the nation, and with a translation into English, the work of the Council soon became popular outside Denmark as it is a mutual international problem. [Watch a video from the presentation of our work with climate-damaging foods \(in Danish\)](#)

In 2016, the Council also addressed the question of how the health service can ensure an ethically acceptable influence of citizens in the use of information, recruitment and recommendations, for example, in connection with screening programmes. Our work led to the issuance of an [ethics checklist](#) aimed to make it easier for municipal, regional and government staff to ensure an ethically acceptable influence of citizens in public health interventions.

In November, the second part of our work with the ethical consumer was published in the form of recommendations to label food from animals fed GMO. [Watch a video from the announcement at Christiansborg \(in Danish\)](#)

Towards year-end, we published the first part of our work with end-of-life ethics, addressing the issue of how to ensure the self-determination of citizens whose lives are coming to an end. Should it be possible to renounce the right to resuscitation if you collapse with a heart attack? And how do we become better at focusing on the values and wishes of the individual when life is coming to an end? [See our recommendations here \(in Danish\)](#)

Part two of this work is starting in 2017 and will cover discussion papers with cases, texts and interviews targeting frontline staff who interact directly with patients.

In January 2017, we are delighted to welcome six new members of the Council.

We will also be starting our work with wearables to put focus on the devices that we carry around, collecting endless data about our health, so we increase our options of tracking our own health and diagnosing ourselves. Wearables add to the huge amounts of data already being recorded by all the devices and services that we use every day – mobile phones, Facebook, etc. The new possibilities of not only collecting, but also storing, analysing and sharing large volumes of data, including health data, are a serious challenge to our privacy and private sphere as we know them today.

The Danish Minister of Health has requested the Council to perform an ethical review of both presumed consent and informed consent in organ donation as well as discuss the ethical issues linked to permitting the anonymous donation of a kidney from a living donor.

The National Committee on Health Research Ethics has approached the Danish Ministry of Health, pointing out that the current provisions of the Danish Health Act and the Committee Act do not adequately address situations involving the transplantation of an organ from a brain-dead donor in which it is desirable to do registered research on the transplanted organ to optimise future treatment. The Danish Minister of Health has requested the National Committee on Health Research Ethics and the Danish Council on Ethics to issue a joint opinion, reviewing



health research ethics and ethics of a more principal and general nature to assess if it should be permitted, through legislative change, to do research on organs taken from a brain-dead donor. The Danish Council on Ethics expects to deliver its reply together with its reply to the Minister's inquiry about presumed consent in organ donation.

Personalised Medicine is another topic that the Council will continue to follow. We provide regular input on how to ensure an ethical framework for the implementation of personalised medicine and spread awareness about the importance of keeping citizens informed and involving them in essential debates about consequences and opportunities.

At the request of the Minister of Health, the Council has reviewed the question of whether to legalise double donation whereby both egg and sperm are donated to the woman wanting to become pregnant. [The statement was issued in January \(in Danish\)](#)

Finally, the Council issues new educational material in keeping with tradition. In 2017, we will be issuing material for upper-secondary school about [gene drive](#) – a technique to permanently change the genes of animals and plants to eliminate species that we have so far been unable to combat effectively. Under the heading of ["Embarrassing bodies!"](#), the Ethical Forum for Young People (targeting lower-secondary school children) puts focus on health, beauty, and self-esteem through material to discuss young people's perception of their body and how their body impacts their identity.

In 2016, like every other year, we [responded to a number of consultations](#), issued [new statements](#), published [educational material](#), participated in the [Folkemødet – Denmark's Political Festival on Bornholm](#), engaged in discussions with citizens and pupils every day, and we participated in hundreds of debates throughout Denmark.

And there is so much more to look forward to in the new year.

Enjoy the read!



Gorm Greisen  
Chairman



Christa Lundgaard Kjøller  
Head of Secretariat

## About the Council on Ethics

The Danish Council on 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 of 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 on Ethics at [www.etiskraad.dk](http://www.etiskraad.dk)

### The Danish Council on Ethics held 11 meetings in 2016:

Council meeting no. 306, 21 January  
Council meeting no. 307, 25 February  
Council meeting no. 308, 10 March  
Council meeting no. 309, 21 April  
Council meeting no. 310, 19 May  
Council meeting no. 311, 22 June

Council meeting no. 312, 25 August  
Council meeting no. 313, 22 September  
Council meeting no. 314, 28 October  
Council meeting no. 315, 17 November  
Council meeting no. 316, 15 December

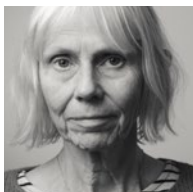
# Members in 2016



**JACOB BIRKLER**  
Chairman  
MA, PhD  
Associate Professor, Teacher  
(resigned 14 February 2016)



**GORM GREISEN**  
Vice-Chair (Chairman from 15 February 2016)  
MD  
Clinical Professor, Consultant



**KIRSTEN HALSNÆS**  
PhD  
Professor



**LENE KATTRUP**  
Doctor of Veterinary Medicine  
Veterinarian  
(resigned 10 March 2016)



**ANDERS RAAHAUGE**  
MA, Theologian  
Cultural Journalist and Parish Priest



**ANNE-MARIE GERDES**  
MD  
Professor, Consultant



**LILLIAN BONDO**  
Midwife, MPA  
Chairman of the Danish Association of Midwives  
(resigned 31 December 2016)



**LISE VON SEELEN**  
Vice-Chair  
(from 15 February 2016)  
Former Head of the Rehabilitation Centre for Torture Victims, Jutland  
Former member of the Danish Parliament



**BOLETTE MARIE KJÆR JØRGENSEN**  
MA in History and Media Studies  
Journalist



Foto: Søren Kjeldgaard

**CHRISTIAN BORRISHOLT STEEN**  
MA in Ethics and Values in Organisations (MEVO)  
Political Consultant



**MICKEY GJERRIS**  
Master of Theology, PhD  
Associate Professor  
(resigned 31 December 2016)



**POUL JASZCZAK**  
MD  
Consultant



Foto: Trine Søndergaard

**CHRISTINA WILSON**  
MA in Art History  
Art Consultant



Foto: Agnete Vistar

**HENRIK GADE JENSEN**  
MA  
Parish Priest  
(joined 9 September 2016)



**SIGNE WENNEBERG**  
Writer, Lecturer  
(resigned 31 December 2016)



Foto: Bente Jæger

**SIGNILD VALLGÅRDA**  
MA, MD  
Professor



**JØRGEN CARLSEN**  
MA  
Principal  
(resigned 31 December 2016)



Foto: Henrik Sørensen  
Kristensen

**KAREN STÆHR**  
Sector President,  
FOA trade union

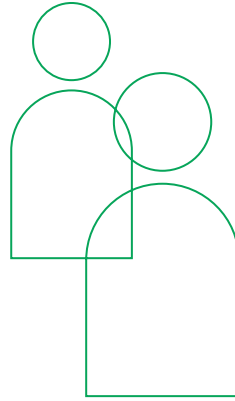


**STEEN VALLENTIN**  
PhD  
Associate Professor  
(resigned 8 September 2016)



**THOMAS PLOUG**  
PhD  
Professor  
(resigned 31 December 2016)

# Debate and dialogue



In 2016, the Council members participated in hundreds of debating events in Denmark organised by universities, hospitals, university extensions, lecture societies, stakeholder organisations, colleges, local church councils, etc.

The Danish Council on Ethics and its members engage frequently in discussions with the national media and are active in debates about ethical concerns and dilemmas through interviews and news and theme broadcasts. The Council and its members also author a number of feature and debate articles in the national newspapers.

Citizens and students contact us daily, and we advise and provide information for use in projects and school assignments through the teaching material on our website and other information.

## **Diagnosis – the best or the worst news**

On Tuesday 26 January, the Council presented its work on diagnosis at an event at Christiansborg. Under the heading "Being diagnosed – the best or the worst news", we wanted to put focus on ethical questions that arise in the use of diagnoses. See page [13](#)

## **The Danish Science Festival**

On 27 April, we introduced our new CRISPR educational material to upper-secondary school students at Køge Gymnasium together with the Danish Science Festival and Videnskab.dk, a Danish research news site. See page [17](#)

## **The ethical consumer: Climate-damaging foods**

On Tuesday 3 May 2016, the Council presented its report on ethical consumption of climate-damaging foods at an event at Christiansborg. See page [15](#)

## **Forum of National Ethics Councils**

Head of Secretariat Christa Lundgaard Kjølner and Thomas Ploug participated in the 21st Forum of National Ethics Councils in Holland from 10 to 11 May 2016.

## **Health nudges – where to set the limits?**

On Thursday 19 May, the topics of nudging and public health were debated, headed by speaker, and former adviser to Barack Obama, Professor Cass R. Sunstein, who is described as one of the founders of the 'nudging' concept. See page [18](#)

## **Folkemødet – Denmark's Political Festival on Bornholm**

From 16 to 19 June 2016, we participated in 26 events at the Folkemødet – Denmark's Political Festival on Bornholm. See page [24](#)

## **Sixth International Conference on Food Studies**

From 12 to 13 October 2016, Council member Mickey Gjerris and Project Manager Anne Lykkeskov participated in the Sixth International Conference on Food Studies at the University of California, Berkeley, USA with the presentation "Is there a moral obligation to reduce meat consumption? The proposal for a climate tax on red meat in Denmark".

## **Gene technology and CRISPR**

On 16 November 2016, the scene was set at Christiansborg for a debate on the use of the CRISPR gene editing technique on human beings, animals and plants.

## **The ethical consumer: Labelling of animal foods from animals fed GMO**

On 16 November 2016, the Danish Council on Ethics published its recommendations on whether to introduce a labelling system for animal foods from animals fed GMO similar to that of food products made directly from GMO. See page [14](#)

» Diagnoses is very much a balancing act; on the one hand, diagnoses – when used properly – refer to real problems – and in this sense, there are several reasons why they are important. The problem, on the other hand, is the way we sometimes use diagnoses – including the way in which the systems of diagnosis develop; they grow, become numerous, and the criteria for using them become broader and broader. As human beings, we tend to look for patterns and categorise everything, and we do the same with human beings who function differently. One of the advantages is that it enables us to learn from our experiences and the knowledge we have gained – it can help us understand the individual human being. But there is a catch: How do we avoid that the diagnosis makes us incapable of seeing you as anything other than what the diagnosis says about you. It is very much about how we use diagnoses – it is not about the diagnosis itself... «

**CARSTEN**  
Psychologist



## Being diagnosed – the best or the worst news

At a debating event in January 2016 at Christiansborg, we presented the results of our extensive work with diagnosis in which we place particular emphasis on what a diagnosis does to the person who receives it. Our presentation came after almost 18 months of talking and interacting with some 110 individuals, people with diagnoses, practitioners, experts, etc., which combined represent a significant share of our endeavours to focus attention on the ethical dilemmas in the use of diagnoses.

Being diagnosed with a disease could be "the best" or "the worst" thing happening to someone; best because it may give clarification, access to the right treatment and new opportunities; worst because a diagnosis can be stigmatising and tie the individual to an unwanted identity.

During the past few years, society has become increasingly aware of the use of diagnosis.

The Council has decided to look at the diagnoses of ADHD, depression and functional disorders because more and more Danes are given these particular diagnoses, and because each diagnosis highlights important ethical themes associated with living with – and giving – a diagnosis.

The material is based on a number of key texts that describe various approaches to using and understanding diagnoses. The texts (in Danish) can be downloaded from our website where you can also find interviews and footage from workshops and the debating event held in January 2016.

Find out more at: [www.etiskraad.dk/diagnoser](http://www.etiskraad.dk/diagnoser)



# The ethical consumer



In the autumn of 2016, we published our report on the phenomenon of *The Ethical Consumer* – the notion that consumers through their consumption take responsibility for the ethical problems that food production may cause.

The ethical consumer is concerned with ethical problems, such as the impact of products on the environment and the climate, excess consumption of scarce resources, problematic perspectives on nature, poor animal welfare, etc. The report discusses if, in some situations, consumers could be said to have an obligation to take such considerations into account, and if, in some cases, we should impose regulatory instruments such as prohibitions, taxes or labelling instead of leaving the responsibility to the individual consumer.

The Council has considered ethical consumption in two areas that some believe are ethically problematic when it comes to food production: *Food from animals fed GMO and climate-damaging foods*.

## Food from animals fed GMO

In Europe, there is persistent consumer opposition to genetically modified crops – a resistance that is unaffected by scientific risk assessments showing that there is no evidence that the use of GMO in itself causes adverse health and environmental impacts.

Some consumers have expressed a wish to extend the labelling of GMO-containing food products to cover also food produced from animals that are fed GMO.

A large majority of members support such a labelling system as it would respect the views of many Danes who still feel insecure about GMO and should have a possibility to avoid these products. It had been a mistake in the past not to listen to people's concerns about gene manipulation of food, and it makes people feel even more insecure.

The majority, however, disagrees that genetic manipulation is more problematic than traditional farming, which also causes radical changes to plants and animals. Ideally, all new plants, non-GMOs included, should be assessed based on their potential risks and potential benefits. The Council encourages that GMOs

Restaurant owner Christian F. Puglisi in conversation with Professor Jørgen E. Olesen at a debating event hosted by the Danish Council on Ethics on 3 May 2016 ([watch presentation in Danish](#)) ▶



be developed to solve the significant challenges of ensuring the nutrition of poor people and to grow in climate-challenged territories, etc.

## Climate-damaging foods

Climate change is an ethical problem because it inflicts serious harm on other people, firstly those living in warmer parts of the world, secondly ourselves and our descendants. Food products account for 19% to 29% of global anthropogenic greenhouse gas emissions, of which cattle alone account for about 10% of the emissions.

Given these figures, major benefits could be in store for the climate – and thus all the people who are affected by global warming – if especially the populations in the western countries were to convert their food purchases to more climate-friendly behaviour. This would especially require a reduction in the consumption of meat from ruminants, which emit large amounts of the greenhouse gas methane.

We are usually free to buy what we want as long as we do not inflict serious harm on others. But there are, in fact, many indications that the production of certain foods does cause serious harm to others through the emission of greenhouse gases. And that is why we should be discussing if the individual has some degree of ethical responsibility to respond to these issues – and in what ways. Today, the choice of whether to consume in a climate-friendly manner is left entirely to the ethical consumer.

A large majority of the Council recommend to start with the imposition of a climate tax on beef, undoubtedly the most climate-damaging food. The main reason is beef's massive contribution to climate change, which is an ethical problem because it harms other people and is a serious threat to the global society's development and the nature.

Find out more about our work with the *ethical consumer* at: [www.etiskraad.dk/etiskforbrug](http://www.etiskraad.dk/etiskforbrug)



# Statement on genetic editing of future humans

In the spring of 2016, we published a statement with recommendations on the use of the new CRISPR gene editing tool that can be used to edit the genes of future human beings.

Over the last year, the use of gene technology to modify humans and future humans has spurred on international debate, not least prompted by the emergence of a new technology known as CRISPR, which can be used to edit our genetic material.

What makes CRISPR different from other known gene editing techniques is that it is cheap, easy and quick to work with. And it has made it widely accessible to a lot of researchers with the result that thousands of researchers are now working to refine it. Before long, we may even see the method being used to genetically modify human beings.

It has reopened the ethical debate about the possibility of modifying genes of fertilised eggs to remove susceptibility to disease before birth, including whether the technique might one day be used to enhance normal traits.

The statement presents the Danish Council on Ethics' recommendations on whether it should be allowed to use genetic modification to remove susceptibility to disease in future children in order to give birth to a healthy child – should it become technically possible.

A majority of members find that it is unethical to permit genetic modification of future human beings, primarily due to the major risks it imposes on future children. A minority of members are, in principle, in favour of the possibilities if the technical problems the methods are facing today can be overcome.

Read more in the statement at: [www.etiskraad.dk/etiske-temaer/genteknologi/publikationer/genetisk-modifikation-af-kommende-mennesker-2016](http://www.etiskraad.dk/etiske-temaer/genteknologi/publikationer/genetisk-modifikation-af-kommende-mennesker-2016)



◀ Professor and Research Manager Jacob Giehm Mikkelsen tells upper-secondary school students at Køge Gymnasium about the development within CRISPR technology. For more information see [www.etiskraad.dk/crispr](http://www.etiskraad.dk/crispr)

## Educational material about CRISPR "Gene technology to treat disease – and to enhance human beings?"

The Council also published educational material targeting upper-secondary school together with the statement.

The development of a new gene editing technique called CRISPR has made it easy, cheap and quick to edit genes, meaning that we can treat diseases and one day perhaps even genetically "enhance" human beings. It will raise numerous ethical dilemmas that will affect today's generation of young people as they are the ones who will have to live with the benefits and the unknown risks that the CRISPR technology is associated with.

The educational material comprises an up-to-date review of research development and the use of gene technology in humans. The material is intended for interdisciplinary learning in upper-secondary school and is ideal for biology/biotech, philosophy and religion classes. The educational pamphlet (in Danish) is available at the Council's website.

Find the educational material at: [www.etiskraad.dk/undervisning/crispr](http://www.etiskraad.dk/undervisning/crispr) and watch the video from the launch at Køge Gymnasium: [www.etiskraad.dk/etiske-temaer/genteknologi/undervisning-til-gymnasieskolen/genteknologi/debat-paa-koege-gymnasium](http://www.etiskraad.dk/etiske-temaer/genteknologi/undervisning-til-gymnasieskolen/genteknologi/debat-paa-koege-gymnasium)

# Nudging – about the use of indirect influence to promote public health

How can the health service ensure an ethically acceptable influence of citizens through information, recruitment and recommendations? Since the summer of 2015, we have worked with "nudging and public health" with the aim of examining the limits and opportunities of systematic use of *indirect influence* – more specifically when the health service uses indirect influence systematically to promote public health.

It can be a challenge to ensure citizens have sufficiently good opportunities to make reflected choices about whether to participate in health-promoting offers. This is evident from the recent years' criticism of the authorities' handling of information in, for example, the screening area. At the same time, especially in the USA and the UK and to a lesser degree Denmark, there has been a growing political interest to "nudge" people, i.e. to make them make better health choices through indirect influence, rather than through information and dialogue.



In the autumn of 2016, it gave rise to a debating event at Aalborg University, to which we had invited one of the founders of the nudging concept to speak on the topic: former adviser to Barack Obama, Professor [Cass R. Sunstein](#). The Council moreover held a number of meetings with the Danish Regions and selected municipalities to get insights into the challenges they face when working with health promotion every day.

An example of indirect influence is when people are automatically invited to participate in screening or immunisation programmes, unless they have actively opted out. As a result, participation rates are often significantly higher and perhaps also more socially balanced compared to if

◀ Cass Sunstein at a debating event at Aalborg University, Copenhagen

they had to register actively. But the effect could also be that people participate because they have blind faith in the system.

The work culminated in the spring of 2016 with the issuance of an [ethics checklist](#) and a [policy paper](#) with recommendations.

A unified Council recommends for the authorities to perform an ethics review when they reach out to citizens with public health offers. The ethics checklist can help municipal and regional staff ensure an ethically acceptable influence of citizens in public health interventions, e.g. information campaigns or outreach efforts.

A majority of the Council members recommend that the obligations of the authorities be specified in legislation. When citizens are exposed to risks and disadvantages that are comparable to those patients are exposed to, the citizens should have the same possibilities of making reflected choices.

However, a minority of Council members do not find that a legal specification is the right way to follow for the very reason that it might inhibit initiatives that promote health and health equality. The choice of whether to use indirect influence should instead be based on an assessment of the advantages and disadvantages in the specific case.

Read more about our work at: [www.etiskraad.dk/nudging](http://www.etiskraad.dk/nudging)

» It could make good sense to participate in screening examinations even though there may be risks involved, but it should be the citizen who decides rather than the health service. «

**THOMAS PLOUG**  
Chairman of the  
working group



# Statement on multifoetal pregnancy reduction

Should a pregnant woman be free to choose multifoetal pregnancy reduction up to and including the 12th week of pregnancy, thus treating multifoetal pregnancy reduction the same way as induced abortion? The Danish Council on Ethics issued a statement in the autumn of 2016, but is divided on the matter.

Under current Danish legislation, a pregnant woman may not herself decide on multifoetal pregnancy reduction before the end of the 12-week abortion limit. Multifoetal pregnancy reduction is permitted only under certain conditions, among other things if the reduction will significantly reduce the risk of deteriorating the woman's health or the health or viability of the fetuses. Under these circumstances, it is permitted to reduce the number of fetuses to two, but under normal circumstances not to one.

In Norway and other countries, the pregnant women can decide on multifoetal pregnancy reduction; multifoetal pregnancy reduction and induced abortion are regulated by the same rules and thus take place under identical frameworks.

The question is if the conditions under which induced abortion and multifoetal pregnancy reduction are performed should still be different in Denmark? Or if the conditions should instead be identical, allowing women to choose to have multifoetal pregnancy reduction before the end of the 12th week of pregnancy and thus to lawfully reduce the number of fetuses to one without reason.

## Opinion: The rules on abortion and multifoetal pregnancy reduction should be different

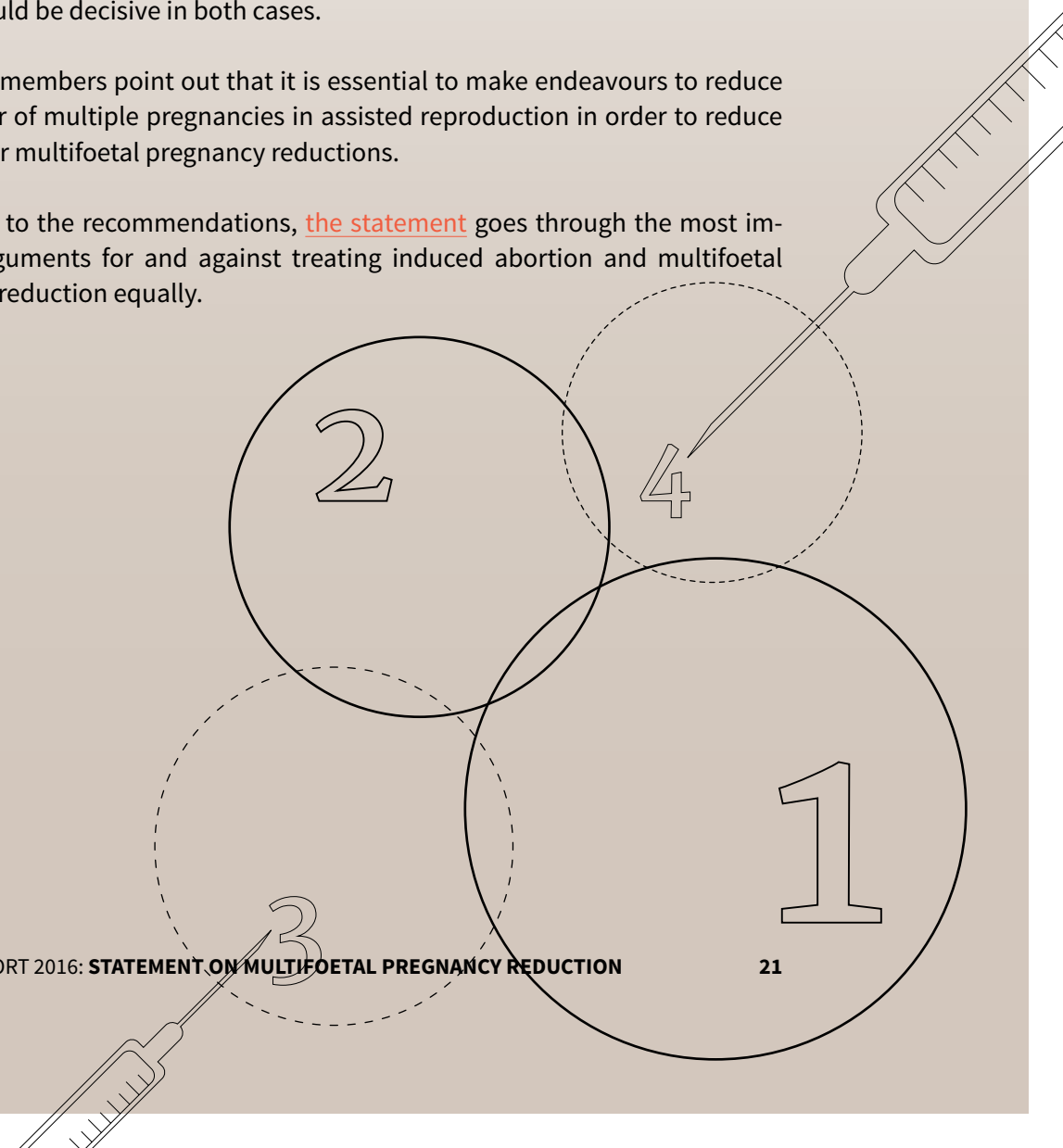
Nine of the Council members support the current legislation. These members find that induced abortion and multifoetal pregnancy reduction differ ethically from one another. In induced abortion, the pregnant woman is opting out of motherhood, but in multifoetal pregnancy reduction, the motherhood is wanted, yet, the woman does not want to develop and give birth to all fetuses of the pregnancy, but wants to remove, for example, one of two fetuses. The members find that this does not express adequate respect for fetuses as human beings.

## Opinion: Equal treatment of induced abortion and multifoetal pregnancy reduction

Eight members of the Council find on their part that a pregnant woman should be free to choose to undergo multifoetal pregnancy reduction before the end of the abortion limit in the 12th week of pregnancy. These members consider it a paradox that a pregnant woman has a free choice of induced abortion of all fetuses in a multiple pregnancy, but has no possibility to keep one or several of the fetuses and remove the rest. The members find that the woman's self-determination should be decisive in both cases.

All Council members point out that it is essential to make endeavours to reduce the number of multiple pregnancies in assisted reproduction in order to reduce the need for multifoetal pregnancy reductions.

In addition to the recommendations, [the statement](#) goes through the most important arguments for and against treating induced abortion and multifoetal pregnancy reduction equally.





# End-of life ethics

Death is a fundamental consequence of human life, but how we die is a different matter. Some die in an intensive care unit surrounded by medical equipment after long-term and exhausting treatment. Others refuse treatment and die at home, in a nursing home or in a hospice.

The individual human being does not always die or live the final days of life according to his or her wishes. We might not always be in a position to change this, but in many situations, there is actually something we can do. To change matters, we need to focus on the values, hopes and wishes of the individual at the right time and place.

It is not an easy choice not to resuscitate if you are not entirely sure if the unconscious person in front of you wants to die peacefully. It must be agreed beforehand.

It is not an easy choice to die at home if it means you lose your possibilities of receiving adequate care. That is why palliative care should be improved.

It is not easy to advise a dying patient about the treatment ahead if you do not know the individual's wishes and hopes for the final days of life. End-of-life discussions are needed before it comes this far.

In the statement [Ethical considerations about self-determination and palliative care in the final days of life](#) (in Danish), the Danish Council on Ethics discusses some of the possibilities and challenges of putting focus on the individual's values and wishes in the final days of life.

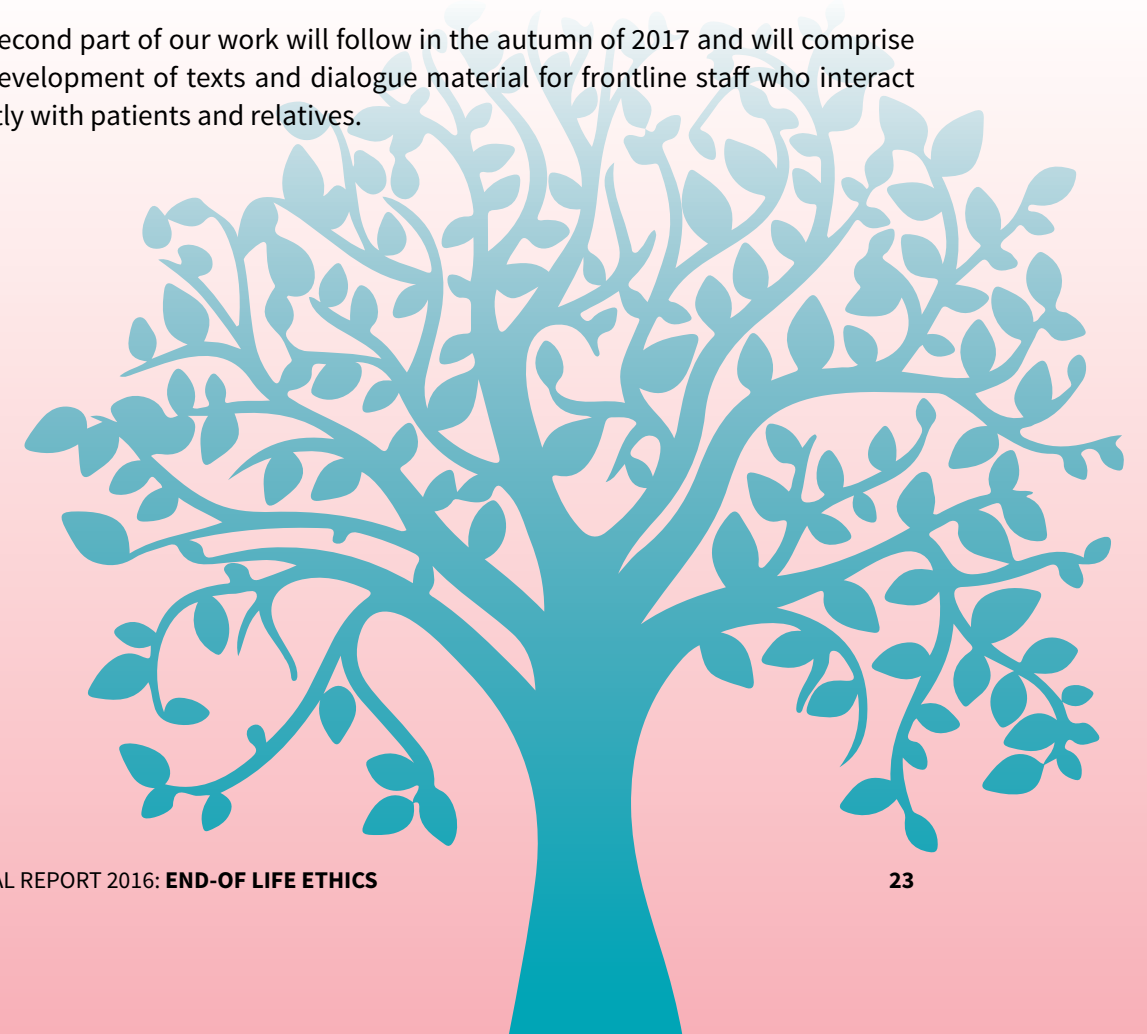
The treatment paradigm in the health sector is an example of such a challenge, because it focuses on life-sustaining technologies and medicinal possibilities, but fails to deal with what is important and valuable to the individual in the final stage of life.



[The statement](#) was issued in December 2016 and represents the first part of our work with ethical dilemmas associated with end-of-life matters.

- We must increase our efforts to ensure that people are not resuscitated (or attempted to be) against their wishes in case of heart failure.
- Healthcare staff are obliged to have discussions with patients in hospitals, residents in nursing homes or people at home if it is very likely that he or she is inevitably dying and at risks of becoming uncontactable or otherwise in no capacity to make decisions.
- As part of the overall care pathway, the offer for palliative care should be better, in the meaning of early prevention and alleviation of pain and other problems of a physical, psychological, psycho-social or spiritual nature.

The second part of our work will follow in the autumn of 2017 and will comprise the development of texts and dialogue material for frontline staff who interact directly with patients and relatives.



# Folkemødet 2016 – Denmark's Political Festival on Bornholm

26 events in three days and a large turnout for our debate about climate-damaging foods. There is no denying that the Danish Council on Ethics was strongly present at the Folkemødet. Our trip to the city of Allinge on Bornholm provided intense debates, inspiration and networking.

In 2016, the Council was represented by members Mickey Gjerris, Thomas Ploug and Steen Vallentin, who participated in altogether 23 debates from Thursday to Saturday.

The debates explored widely different topics: artificial intelligence, bowel cancer screening, climate change, food consumption, private/public healthcare collaboration, big data, dignity in elderly care, diagnostic culture, euthanasia, personalised medicine, pre-birth diagnosis and organ donation.

Steen Vallentin moderated the debate on end-of-life ethics, introducing the expression of 'active help until death' as a way of expressing the balance between palliative care and euthanasia. Thomas Ploug headed a number of other debates on the use of health data and made people reflect and understand the idea of introducing more varied forms of consent.

## WHY WE PARTICIPATE AT THE FOLKEMØDET:

We cross debate swords with organisations, politicians and citizens

We put questions of ethics on the agenda

We reach many people that we do not reach in our daily work

We establish new contacts and raise awareness about our work

Last, but not least, we are confirmed that the political debate in Denmark is alive and kicking.

The Council closed this year's Folkemødet on Saturday at noon in the quarters of the Danish Board of Technology Foundation. Under the heading 'Tax on beef?', we invited people to join our debate about the climate, food products and consumer responsibility.

It is fair to say that far from everyone agreed to put a tax on beef. Mickey Gjerris, Chairman of the working group on *the ethical consumer*, explained that a tax on beef cannot do it alone, but that it is meant as a first step of a strategy designed to make us consume in a way that does not pass on the bill to coming generations.

For more information about our participation at the Folkemødet, please see: [www.etiskraad.dk/fmdk/2016](http://www.etiskraad.dk/fmdk/2016)



◀ There was a great interest for our debate on climate, food products and consumer responsibility



# Consultation responses 2016

**The Council has received a total of 29 consultation letters, 12 of which gave rise to elaborative responses:**

18 January 2016: Response to consultation on draft bill to amend the act on clinical trials for human use

25 January 2016: Response to consultation on draft bill to strengthen efforts towards pregnant women with alcohol and drug abuse

29 February 2016: Response to consultation on guideline about information security in the health services

2 March 2016: Response to consultation on draft bill to amend the act on insurance contracts and act on supervision of pension funds

11 March 2016: Response to consultation on draft bill on the strengthening of the Danish Patient Safety Authority's supervision of treatment facilities and health-care professionals. We have especially addressed the authorities' possibilities of exchanging information about medical prescriptions traceable to physicians and patients.

18 April 2016: Response to consultation on guideline on pre-treatment wishes, treatment plans, etc. for patients admitted to psychiatric departments

24 May 2016: Response to consultation on two executive orders: Executive order on national and regional clinical quality databases and executive order on reporting to authorised clinical quality databases and disclosure of data to the Danish Health Data Authority

7 June 2016: Response to consultation on the amendment of the executive order on assisted reproduction

21 June 2016: Response to consultation on draft executive order to change the executive order on the choice and replacement of general practitioner and on treatment by a doctor in the practice sector

1 August 2016: The Danish Council on Ethics' comments on draft to revise the guidelines on pre-birth diagnosis

17 August 2016: Response to consultation on two draft executive orders and guideline on the disclosure of information from the Danish Health Data Authority's Register of Medicinal Product Administration and Register of Medicinal Product Statistics

23 August 2016: Response to consultation on draft executive order on the right to hospital treatment, etc., draft executive order on the entering of agreements under the extended free-choice schemes, etc. and guideline on free choice of hospital, extended free choice of hospital, right to prompt assessment and information to referred patients

30 November 2016: Response to consultation on draft bill to amend the Danish Health Act (better use of health information, etc.)

8 December 2016: Response to consultation on executive order on the use of force and reporting in case of restraint of drug abusers in treatment

8 December 2016: Response to consultation on executive order on the use of force and reporting in case of restraint of pregnant alcohol abusers in treatment

20 December 2016: Response to consultation on draft bill to amend the act on the right to complain and receive compensation within the health service and draft executive order on reimbursement of psychological treatment in the practice sector for particularly vulnerable groups.

See all consultation responses at: [www.etiskraad.dk/hoeringssvar](http://www.etiskraad.dk/hoeringssvar)







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