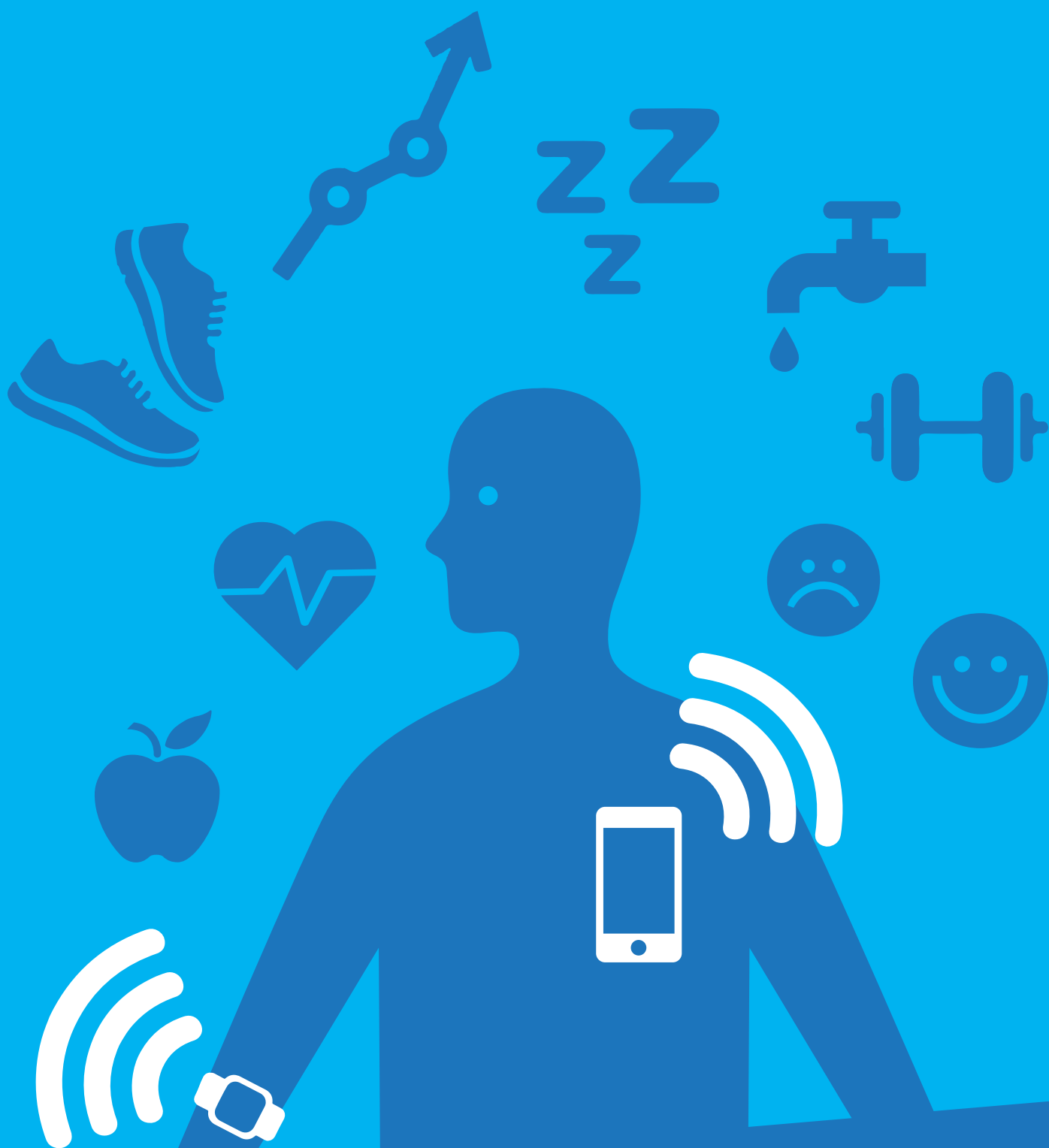


ANNUAL REPORT 2017



THE DANISH
COUNCIL
ON ETHICS

Annual Report 2017 of the Danish Council on Ethics

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Preface

The Annual report provides insight into some of the projects the Danish Council on Ethics worked with during 2017.

At the turn of the year, one third of the Council's members stepped down after their six years in the council, and we welcomed six new members in January 2017.

Shortly after, the Council selected topics for its workplan: Wearables and big data, Prioritisation and Early detection. The working groups addressing these topics will complete their work in 2018, and we encourage everyone interested to follow our activities via our website, newsletter and Twitter.

In late 2016, the Minister of Health requested the Danish Council on Ethics to consider various ethical questions related to organ donation, including the advantages and disadvantages of anonymous donation from living donors and the question of presumed consent and informed consent in organ donation. The Council published two statements in June 2017, which you can read more about on the next pages. You can also read about the Council's other topics in 2017.

The Danish Council on Ethics will be moving to Kolding in Jutland in January 2019 as part of the Danish government's relocation plans. Sadly, the relocation means we will be saying goodbye to our skilled and experienced project managers who have organised the preparation of the Council's reports and statements in the past 9 to 23 years. The Council would like to extend a special thanks to them for their hard work through the years.

2018 and coming years will inevitably be about digital development and the use of data. When the Danish Parliament established the Danish Council on Ethics in 1987, it did so because gene and reproduction technologies had begun to challenge what until then appeared to be fundamental: the way human beings come into existence and the genetic composition they receive. Now, humans could "interfere" with these fundamentals, and the need arose to establish ethical and legal rules for how this was to take place.

Similarly, the digital development is pushing something fundamental in our society: namely our possibilities of privacy, of being forgotten, of gaining overview and control despite increased technology dependence. The way we look at it, it also exposes us to substantial risks if the legislature does not rise to the challenge.

The scale to which data have grown and the fact that they are stored, shared and processed on such a huge scale, makes it possible for both private and public entities to gain access to comprehensive, personal knowledge about every citizen – and without their knowledge. This knowledge can serve good and bad purposes, as reported frequently by the media lately.

The Danish Council on Ethics is currently looking at the use of the digital health data that are being collected by what is known as 'wearables' such as mobile phones and smartwatches. As in other areas, there is no doubt that digitalisation will have considerable potential in the healthcare area. Partly by offering better, more personalised and more effective treatments and better prevention of disease, and partly by promoting self-care and offering choices. The potential efficiency gains may also help fight the demographic challenges made up of increased demand for services requested by a growing population of elderly people in the coming years.

At the same time, we expect an increased focus on healthy lifestyles rather than treatment; citizens must be kept in good health and must themselves play an active role to prevent disease. Self-reported and self-collected data could form the basis for advice about healthier lifestyles. Research is being done to cross-reference such data with data from other sectors to become even better at predicting who is at risk and who to reach out to with offers for guidance.

Many will undoubtedly appreciate being approached in this way, but others might find it invasive. Being healthy could end up being presented as the most important value and as an obligation. But not everyone wants to put health before other things which to them is what makes a good life. Since the data concerned are objective data on actual behaviour, it can be questioned what is and what is not self-caused, and the risk of individual stigmatisation and discrimination might arise. Other important questions concern the possibilities of identifying risk groups which could then be treated differently at group level – positively or negatively.

These are just some of the ethical dilemmas that increase with the digital development, and the development is moving fast. Data ethics must therefore be put on the agenda, and the Danish Council on Ethics will work in that direction.

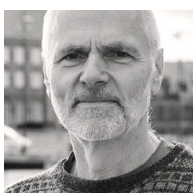
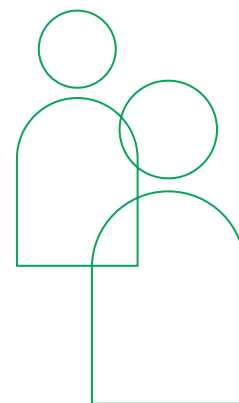


Gorm Greisen
Chairman



Christa Kjoller
Head of Secretariat

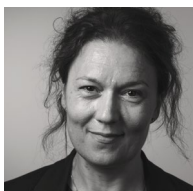
Council Members 2017



GORM GREISEN
Chairman
MD
Clinical Professor
Chief Physician



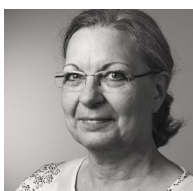
LISE VON SEELEN
Vice-Chair (until August 2017)
Former member of the Danish Parliament



BOLETTE MARIE KJÆR JØRGENSEN
Vice-Chair (from August 2017)
MA
Journalist and Historian



ANDERS RAAHAUGE
MA
Theologian
Cultural Journalist
Vicar



ANNE-MARIE GERDES
MD
Head of clinic, Professor and Chief Physician



CHRISTIAN BORRISHOLT STEEN
MA
Political Consultant

Foto: Søren Kjeldgaard



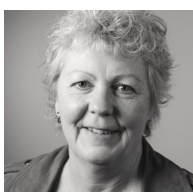
EVA SECHER MATHIASEN
MA Psychology
Chair of Danish Psychological Association

Foto: Claus Bjørn Larsen

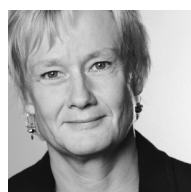


HENRIK GADE JENSEN
MA
Vicar

Foto: Agnete Vistar



HERDIS HANSEN
Nurse
Hospice chief



KAREN STÆHR
Former Sector President,
FOA trade union

Foto: Henrik Sørensen



KIRSTEN HALSNÆS

PhD
Professor



MIA AMALIE HOLSTEIN

MSc and MA
Head of welfare policy,
Cepos



MORTEN BANGSGAARD

Student of Theology
Former secretary general
and former CEO



POUL JASZCZAK

MD
Former Chief Physician



**RUNE ENGLBRETH
LARSEN**

MA
Writer, Photographer,
Lecturer



SIGNILD VALLGÅRDA

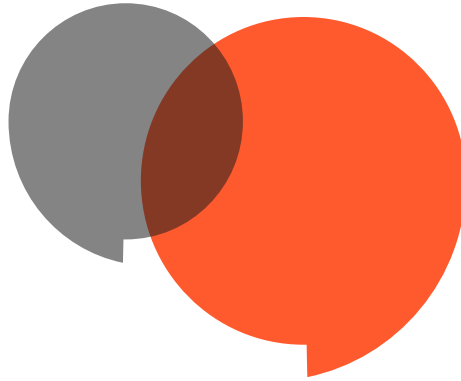
MA, MD
Professor

Foto: Bente Jæger



**THOMAS SØBIRK
PETERSEN**

PhD in Philosophy
Professor



On 1 January 2019, the Danish Council on Ethics will move to Kolding in Jutland as part of the Danish government's relocation plans. Sadly, the relocation means we will be saying goodbye to our skilled and experienced project managers who have organised the preparation of the Council's reports and statements in the past 9 to 23 years.

There is no doubt that being a project manager at the Danish Council on Ethics requires special competences and is a difficult balancing act. The job requires a high degree of expertise; an ability and desire to immerse oneself in demanding topics; knowledge of political processes; a large network of experts with knowledge to draw on; and an ability to communicate and convey topics to citizens, students, politicians, journalists and experts.

And last but not least, it requires the civil servant's special ability to walk a tight-rope. Writing the Council's reports and statements requires humility and attentiveness to the Council's arguments and opinions. But it also comes with the job to challenge the Council in order to ensure the arguments are strong and durable to support the Council's task in society in the short and long term.

The collaboration gives rise to professional exchange, innovation, discussions, joy and sometimes frustration for both the Council and the secretariat. This is what makes the Danish Council on Ethics one of the most exciting places to work at in Denmark. It is a workplace where we consider ourselves privileged because we get the chance to gaze into the crystal ball to see which new ethical dilemmas we as a society need to prepare for.

The four project managers have done outstandingly well. We wish to extend our warmest thanks to you for your impressive contributions which we as Council members have enjoyed thoroughly through the years.

We wish you the best of luck in the future.

The members of the Danish Council on Ethics



Debates and events in 2017

Talks about euthanasia

On 5 April, the Danish Council on Ethics organised evening talks about euthanasia. Lisa Grye Elstorp and Søren Saustrop Gersby, founders of the association “Retten til at dø” (the right to die), wanted to put focus on euthanasia in collaboration with the Danish Council on Ethics. The talks were also joined by the association “Ikke død endnu” (not yet dead) and the Danish Medical Association.

[Read more on our website](#) (in Danish)

CRISPR and gene drive for eradication of unwanted species

In collaboration with the Danish Science Festival, the Danish Council on Ethics announced a new web-based educational material which addresses the dilemmas created by the new gene technologies known as gene drive and CRISPR. The event took place at Roskilde Gymnasium and via live streaming to 36 participating upper secondary schools across Denmark on 26 April 2017. Here, the participating researchers and ethicists presented the material and debated the ethical implications imposed by the technologies with more than 1,500 upper secondary students from across Denmark.

[Watch the video on YouTube](#) (partly in English)

Wearables and big data

On 6 November 2017, the Danish Council on Ethics organised a debate on the future’s healthcare sector and how the use of wearables and data will play an important role in prevention and treatment in the healthcare sector of tomorrow.

[See more about the project on wearables and big data](#) (in Danish)

Personalised medicine theme discussion

On 7 September, our Steering Group on Personalised Medicine was invited to a discussion on the evolution of personalised medicine by the Healthcare Committee of Danish Regions. The purpose was to have a common reflection on the ethical questions that personalised medicine raise. Together with Danish Regions, the Council has developed a case-based discussion paper on the ethical dilemmas that are linked to the development in personalised medicine. [The case material is in Danish and can be found on the Council’s theme page on personalised medicine](#). Here the Council’s other publications of relevance are also briefly described.

Folkemødet 2017 – The People’s Political Festival

For the fourth year in a row, the Danish Council on Ethics participated at the People’s Political Festival, a political festival on Bornholm. The People’s Political Festival provides ample opportunity to raise awareness of the Council’s current work and test new formats for communicating and conveying information. The People’s Political Festival is also an important venue for us to fulfil our statutory obligation to generate public debate and engage directly with citizens and stakeholders.

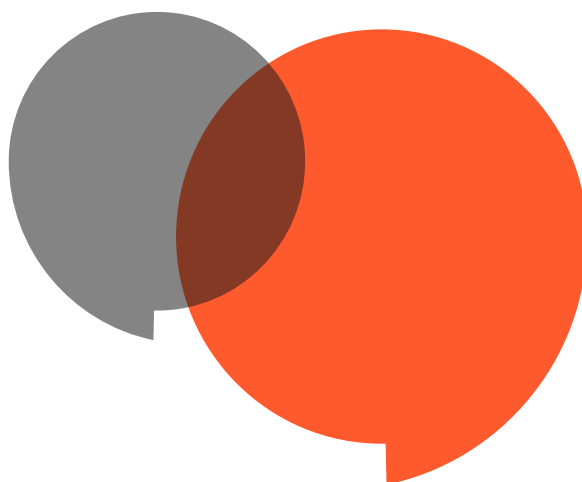
In 2017, the Council was represented by Gorm Greisen and Poul Jaszczak, who participated in 10 debates over two days.

[See video clips from the People’s Political Festival from 2017](#) (in Danish)

Other debate activities

During the year, the Council members also participated in numerous debating events in Denmark organised by universities, hospitals, university extensions, lecture societies, stakeholder organisations, folk high schools, local church councils, etc.

The Danish Council on Ethics and its members engage frequently with the national media and are active in debates on ethical questions and dilemmas by participating in documentaries, news and theme broadcasts. In addition, the Council and its members author a number of feature and debate articles in the national newspapers.



EMBARRASSING BODIES!

ABOUT HEALTH, BEAUTY AND SELF-ESTEEM

In autumn 2017, the Council published its educational material for lower secondary school (age 14 to 16). This year's theme was the body and ethics, including the importance of the body on the identity of young people. The edition of 12,000 copies was sold out quickly, but the material is still available from our website.

The body is inseparably bound to our lives. The body is a condition for living, and as such it is an important organism that needs nourishment and looking after. The body belongs to ourselves, but also interacts through the relations we have with other people by visually showing our outward appearance. It shows where in the world we live, if we are rich or poor, and we also use our body to tell other people who we are – or who we would like to be. So, the body is both a casing and a part of our identity. We have a body, and we are a body at the same time.

The body and ethics are about how we see ourselves and how we see others. When we discuss the ethics of the body with others, it becomes evident how important it is that we treat each other properly. And that when we accept others, it becomes easier to accept ourselves.

The Danish Council on Ethics wants to promote a culture where young people are happy with their body. No two bodies are alike – and that’s a good thing! All human beings are different and therefore unique.

In Kropumulig! (Embarrassing bodies!) you can read about how the society you are born into has a great impact on how you look at your body. You can read more about body ideals, for good and bad, and you can learn how some people struggle to accept their own body.

In the leaflet, you will meet Lasse during a fitness session and join Faye Sarmady at work in the beauty clinic. You will also meet Helle whose daughter suffers from a serious eating disorder, and Sephyr who was assigned the female gender at birth, but today wants to meet with other trans-masculine persons.

The edition of 12,000 copies was sold out quickly, but the material is available for free on our website together with supplementary interviews and assignments.

EDUCATIONAL MATERIAL

With the material Kropumulig! (Embarrassing Bodies!), the Danish Council on Ethics wants to spur a debate on the importance of the body on young people and their development. The educational material is in Danish and is aimed at pupils in lower secondary school (age 14 to 16) and deals with how young people feel about their body and the importance it has for the identity of young people. The material can be used in class as a discussion paper, or as inspiration for project assignments or cross-disciplinary project work.

Download the material from our website (in Danish): www.etiskraad.dk/kropumulig

ETHICAL FORUM FOR YOUNG PEOPLE

Kropumulig! (Embarrassing Bodies!) is a material in Danish published as part of the educational material in the Ethical Forum for Young People. The Ethical Forum for Young People targets lower secondary school students (age 14 to 16).

The aim of the material is to let young people debate ethical questions linked to aspects of society.



The use of gene drive and CRISPR to eradicate unwanted species

Should humans interfere with nature to prevent other species from inflicting suffering and death on human beings – even if the consequence poses a risk of complete extinction worldwide? In the spring of 2017, the Council considered this fundamental question.

Research is being done to suppress or wipe out certain species by releasing these harmful animals and plants into nature after having genetically modified, for example, malaria-carrying mosquitoes to produce non-viable offspring. Using so-called gene drives, it is ensured that the gene modification is passed on to all of the mosquito's offspring as compared to only half in normal inheritance.

In its statement, the Danish Council on Ethics considers the fundamental question if humans should interfere with nature at species level in an attempt to limit entire species that are responsible for large-scale death or suffering, to the extent that the consequential risk is global extinction. It is a risk that cannot be excluded as gene drives do not respect borders. If we were to release genetically modified organisms into nature with the purpose of letting them spread as far as they can, would it constitute an unacceptably high risk of unpredictable side effects or misuse? Or can these risks be handled to an acceptable degree, and is the uncertainty outweighed by the major advantages, e.g. in the form of saved human lives, which the use of the technology might bring? And does the act of trying to control entire species, thus reducing the biodiversity, impact the nature on an unacceptable scale?

The Council's recommendations

The members of the Danish Council on Ethics agree that gene modification in combination with gene drives has not reached a state of maturity to be used in attempts to eradicate unwanted species. Also, it is a technology which at any rate cannot be used without comprehensive authorisation and control systems,

EDUCATIONAL MATERIAL FOR UPPER SECONDARY SCHOOL

In connection with the Danish Science Festival in April 2017, the Council also published new educational material about gene drive. The material is intended for teaching in upper secondary schools, especially for the subjects of biology, biotechnology, philosophy and religion. Besides an introduction and technical background reading, the material also includes interviews with researchers from Imperial College London where they are testing gene drives inserted in malaria-carrying mosquitoes with the aim of rendering the offspring of mosquitoes non-viable and thereby eradicating malaria. See: www.etiskraad.dk/undervisning/gene-drive





WHAT ARE GENE DRIVES?

Gene drives are created using gene technology (the technique used today is known as CRISPR) to alter the genes. The gene drive has the effect that all of the offspring will inherit an altered gene that is being added at the same time instead of just half of the offspring which is the case in normal inheritance. This way, the altered gene will spread very quickly in a wild population.

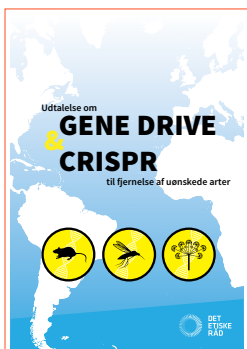
The gene modification intended to spread in a species could for example be an encoder that makes organisms infertile. The purpose could be to eradicate animal species (e.g. disease-carrying mosquitoes). Or it could be to target those plants (e.g. invasive weeds) that humans generally want to get rid of but cannot combat efficiently with other means, e.g. chemical or biological methods.

It is a new research area in which researchers in 2015 have published a total of four trials. These trials suggest that genetic modifications combined with gene drive can spread "destructive" genes to almost 100% in populations in yeast, fruit flies and mosquitoes. Research is being done to use the technique on other species.

including a thorough weighting of the risks and consequences for ecosystems. It would also be necessary to conduct experimental releases and evaluations in each specific case. The members also agree that research into gene drives should continue because it will always be important to conduct research in measures to neutralise "runaway" organisms in the event that it should become necessary to counter any hostile uses of the technology. In addition, it is necessary that both national policy makers and international forums consider if the current legislation is sufficient and take measures to strengthen the regulation in needed areas.

Finally, the members agree that it is important to continue research into alternatives to the use of gene drives, and that the least invasive alternative should always be selected. The work with gene drive technology must not weaken the efforts that are already being taken to solve the concerned disease and mortality problems. Gene drive technology should not be seen as a 'silver bullet' allowing us to leave behind the affected populations in other ways.

However, the members are divided when it comes to deciding if the advantages of the technology, after satisfactory research and experimental releases have taken place, can justify the implementation of the technology in the long term. Two members find that it is too early to consider in principle the terms under which the technology could potentially be implemented.



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

Recommendations on the legalisation of double donation

At the request of the Ministry of Health, the Council issued a statement on the legalisation of double donation in early 2017. The statement discusses different ethical themes, including considerations about the welfare of the child, the right to reproduction and the meaning of being genetically related.

In double donation a woman wanting to become pregnant receives both eggs and sperm from donors. The existing legislation contains a prohibition against this form of donation to ensure the child is genetically related to at least one of the prospective parents. The Danish Council on Ethics has considered if the prohibition should be relaxed in light of today's family structures where many children grow up in families that are entirely different from the traditional nuclear family.

The Council's recommendation

The Danish Council on Ethics supports the implementation of a more liberal legislation. The members find it difficult to see that the mere absence of a genetic relationship in itself can justify the existing legislation. But the members are split when it comes to how far we should go. One of the questions discussed was if a woman in a lesbian couple should be allowed to donate an egg to her partner even if the partner has usable eggs. It would make it possible for both women to feel biologically connected to the child, one by having carried and borne the child, the other by having supplied the egg.

A majority of the Council members find that double donation should only be offered if there is a health-related indication, i.e. in connection with infertility or the risk of a serious disease in the child. This would exclude the above described donation form between women in a lesbian couple, unless the woman receiving the egg is infertile or has a serious genetic disease. These members also find that single women who are either infertile or have a serious genetic disease should have access to double donation.

A significant minority of the Council members support the legalisation of double donation irrespective of the form of double donation. The members cannot see any ethical considerations that decisively speak against a legalisation.

Besides the question of legalisation of double donation, a number of other topics are considered in the Council's statement. For example, the Council has discussed the importance of telling the child that it has come into existence by means of donation. In double donation, problems become twofold compared to other forms of sex cell donation. The question of whether the legalisation of double donation could lead to the legalisation of surrogacy is also a theme in the statement. In addition, the statement presents some of the most important arguments for and against the legalisation of double donation.

At the end of 2017, the Danish Parliament adopted the legalisation of double donation, see retsinformation.dk (link to the Danish bill to amend the law on assisted reproduction)



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

A large part of the content is based on a previous statement from 2014, [statement on embryo and double donation](#), in which many of the themes were described and discussed (statement is in Danish).

Two statements on organ donation

In late 2016, the then Minister of Health, Sophie Løhde, requested the Danish Council on Ethics to consider different ethical issues in organ donation, including advantages and disadvantages of anonymous donation from living donors and the question of presumed consent and informed consent in organ donation. The Council published two statements in June 2017.

Donation of kidney from anonymous, living donor

In one of the statements, the Danish Council on Ethics considers the question of whether it should be possible for anonymous persons to choose to donate a kidney to patients on the waiting list.

The anonymous donation of kidneys from living persons is not prohibited in Denmark, but is not practiced for various reasons. Among other things, it would require the establishment of authorisation procedures for donors and a practice for record keeping to preserve donor anonymity.

The Council's recommendations

A large majority of the members of the Danish Council on Ethics find that it should be possible in future for persons who are of age and capable of making decisions to donate a kidney anonymously. The preconditions include that the person has been fully informed of the health-related consequences of donation and is assessed to be capable of deciding whether to donate based on the information received. Should this donation form be permitted, it will increase the number of kidneys available for transplantation while expressing respect for the donor's autonomy. Also, altruistic donation must be considered a commendable act.

A minority of the members of the Danish Council on Ethics find that the anonymous donation of kidneys should not be allowed or facilitated. They base their view on the fact that such donation, in the short and long term, exposes the donor to a health risk that is not insignificant. Anonymous donations imply that individual persons can be viewed by others and themselves as spare parts for others. Thus, the individual is considered a means and not an objective in itself. This way of looking at human beings should not form the health services' way of working. So, we should at any rate first try to obtain more kidneys for donation in other and, from an ethical viewpoint, less problematic ways.

A majority of the Council members moreover recommend that doctors should be able not to partake in the anonymous donation of kidneys if such donations go against their convictions.

Presumed and informed consent in organ donation

In the other statement, the Council discusses the question of whether we should introduce presumed consent in organ donation, implying that every citizen will be considered as donors by default.

Under the current legislation, either the deceased or his or her relatives must have given their informed consent for donation before organs can be used for transplantations. In presumed consent, you are automatically considered a donor if you do not actively opt out of the system.

The Council's recommendations

A large majority of the Council members recommend that consent for donation should continue to be obtained before organ transplantation can be considered. In these members' opinion, human beings have a legal ownership of their body, preventing others from accessing it or using it without their consent. Inherent in this right is also the right to decide and declare directly what is to happen and what is allowed to happen with your body or the right not to be sure about this. It therefore infringes the deceased person's autonomy and integrity if a consent to that effect has not been obtained.

A minority of the Council members recommend to introduce presumed consent in donation since it must be assumed that this would lead to more transplantations than today's numbers. These members assess that a system of presumed consent would save lives and contribute considerably to the quality of life for many people. And since everyone must be given the possibility to opt out of organ donation, the minority does not find that such a system would infringe the autonomy of citizens.



[Read the statement on donation of kidney from anonymous, living donor \(in Danish\)](#)



[Read the statement on presumed and informed consent in organ donation \(in Danish\)](#)

Consultation responses in 2017

The Danish Council on Ethics received a total of 53 consultation letters, 12 of which gave rise to elaborative responses:

8 February 2017: Response to consultation regarding the bill on the use of coercion in somatic treatment of individuals with permanent incapacity

24 February 2017: Consultation response, bill to establish specialised social-psychiatric centres

17 May 2017: Discontinuation of the Brain Collection at Aarhus University Hospital

June 2017: Consultation response regarding medicinal cannabis

June 2017: Consultation response regarding healthcare assistance in gender identity matters and gender reassignment therapy

16 August 2017: Consultation response regarding bill to lift the prohibition against double donation and change of castration rules

10 October 2017: Consultation response regarding the autonomy of patients in the final days of life

25 October 2017: Consultation response regarding the establishment of a National Genome Centre

30 October 2017: Consultation response regarding coercion in somatic treatment (executive orders)

2 November 2017: Consultation response regarding a comprehensive plan for patients admitted to special hospital places in psychiatric centres

11 December 2017: Consultation response regarding guidelines for medical palliative care in the terminal phase

11 December 2017: Consultation response regarding the act on clinical trials of medicines and act on research ethics review of health research projects

See our newest consultation responses at www.etiskraad.dk/hoeringsvar (in Danish)

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.

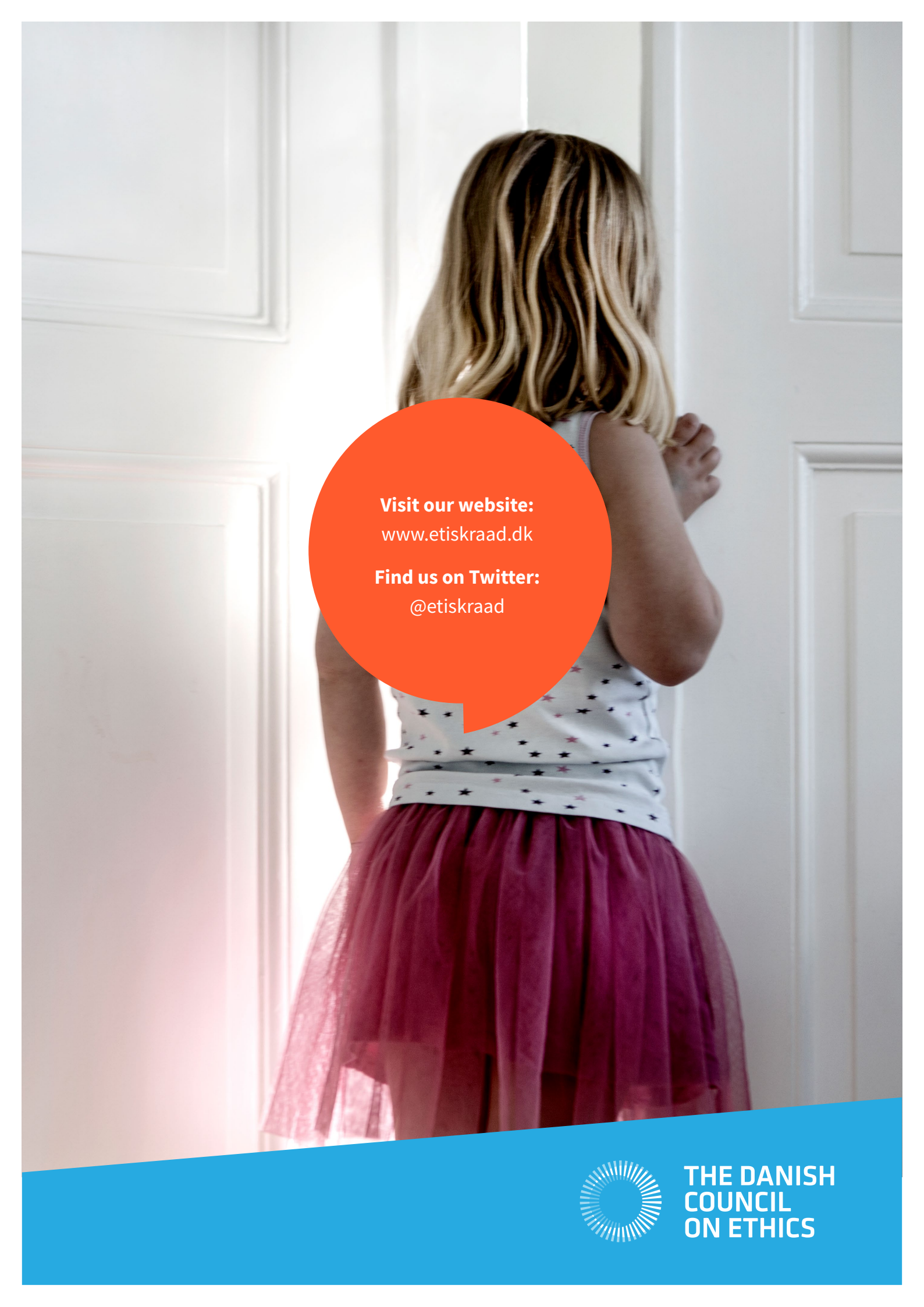
The Danish Minister of Health officially appoints the Council's members. When designating and appointing members, it must be ensured that both laypersons and specialists are represented, and that there is only one more of either sex than the other.

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

The Danish Council on Ethics held 11 meetings in 2017:

Council meeting no. 317, 19 January
Council meeting no. 318, 23 February
Council meeting no. 319, 23 March
Council meeting no. 320, 27 April
Council meeting no. 321, 18 May
Council meeting no. 322, 22 June

Council meeting no. 323, 24 August
Council meeting no. 324, 21 September
Council meeting no. 325, 26 October
Council meeting no. 326, 23 November
Council meeting no. 327, 14 December



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**THE DANISH
COUNCIL
ON ETHICS**