

ANNUAL REPORT

2015



**THE DANISH
COUNCIL
ON ETHICS**

ANNUAL REPORT 2015

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Contents

Preface · 4

Ethical debate in 2015 · 6

Research with health data and biological material in Denmark · 8

Love child (Danish: Ønskebarn) · 10

Storing and use of non-fertilised eggs · 12

**The difficult choice
– challenges for the ethical consumer · 14**

People and politicians meeting 'Folkemødet' on Bornholm 2015 · 16

Consultation responses 2015 · 18

About the Council on Ethics · 19

Members in 2015 · 20

Preface


Health data about the Danish people are being collected on an unprecedented scale. It should benefit patients, research and society in general. In parallel, we are now able to derive a lot of details from the health data available to us. When, for example, we do research on the genes of an individual human being, we can extract information about potential susceptibility to disease, which could have major consequences and generate uncertainty for that individual and his or her family. Ethical dilemmas have followed suite, and they are sharper than ever before.

Over the year, the Danish Council on Ethics looked at how society, given today's circumstances, should weigh different interests, focusing on the values of solidarity, benefit, privacy, trust and self-determination. We asked the following questions to guide us along the way:

- How can we protect the privacy of citizens better?
- How can we promote effective health research based on solidarity?
- How do we preserve citizens' trust in research?
- What role should the citizens' self-determination play?

Our discussions led to a number of recommendations on research with health data and biological material, which you can read more about on page 8.

At the Danish Council on Ethics, we strive to deliver 'timely ethics', but in 2012 when we published our report on the ethical dilemmas associated with genome research not many raised their brows. It turned out that we had delivered 'ethics too early' because the issues we raised then are highly relevant to the considerations that ought to be made today. This was recently brought into focus, among other things by an action plan on personal medicine published by the Danish Regions, projecting to sequence the genomes of 100,000 citizens.



We encourage everyone to appreciate the many considerations that are to help build sustainable solutions and safeguard the rights of each person and the population's continued high level of trust in research and the health services.

More than half of the visitors to our website are pupils and students. We are extremely grateful for their interest because the youth is the next adult generation that is to address the ethical questions that emerge continually with developments in society.

Ethical questions influence the lives of everyone, and we do need to address them. Having said that, there is hardly ever any simple and straightforward answers to these questions, and trying to establish ethical guidelines is best achieved in dialogue with others. Since we want to support this dialogue, the Danish Council on Ethics publishes educational material for elementary and upper secondary school every year.

In 2015–2016, the educational material is about planned children and the choices that must be made when children are brought into this world with help from technology. Questions of donor anonymity, the right to have children and the possibility of 'designing' your own child are relevant questions for today's youth in a time when one in every ten people seeks help to become pregnant and there are 37 different family constellations according to Statistics Denmark.

2015 was a busy year featuring many relevant ethical discussions that will stretch into the years ahead. In this annual report, you can read a selection of these discussions. For a complete overview of all the Council's activities, we refer to our annual financial report (available in Danish only).

Enjoy



Gorm Greisen
Chairman



Christa Lundgaard Kjøller
Head of Secretariat

Ethical debate in 2015

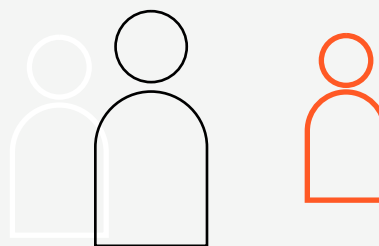
ETHICAL DEBATE OVER THE COUNTRY

We try to be present at as many debating events as possible as we want to lay the basis for ethical discussions across Denmark. During 2015, the Council members participated in more than 100 national debating events organised by universities, hospitals, university extensions, lecture societies, stakeholder organisations, colleges, local church councils, etc. It is especially on our trips across Denmark that we meet face to face with citizens, professionals and politicians.

Here is a selection of some of the presentations we have held:

- Theme day about ethics in the intensive care unit at Sønderborg Hospital
- Presentation at the clinical ethics committee at Hvidovre Hospital
- Presentation at the Sankt Maria Hospice in the city of Vejle about end-of-life dilemmas
- Presentation in the city of Hjørring about the Council's work
- Presentation at the FOA trade union, Zealand, about ethics in the health sector
- Presentation for Danish bioanalysts about ethics and minimal patient contact

The Council provided financial support to the organisation of 27 debating events over the course of the year.



CONTACT TO CITIZENS AND STUDENTS

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.



ETHICAL TOPICS IN THE MEDIA

We talk to the national media frequently and join the debate on ethical questions and dilemmas by participating in documentaries and news and theme broadcasts. We also author several feature and debate articles in the national newspapers. In December 2015, we appeared in the documentary 'Indefra' (literally: From inside) with Anders Agger (Danish Television, DR2, 7 December 2015).

COUNCIL MEETINGS

We held 10 Council meetings and one residential seminar in 2015. The Council meeting in August was held jointly with the Swedish National Council on Medical Ethics.

INTERNATIONAL COOPERATION

Ethical dilemmas often transcend national borders. We therefore try to be represented at a number of international conferences to speak about the Council's activities and exchange knowledge with ethics councils around the world. Some of the events we participated in were:

- The Beings 2015 Summit in Atlanta, 17-19 May 2015, a gathering of leading scientists and bioethics brought together to generate and exchange ideas to reach consensus on the future of human cellular biotechnology.
- The Swedish National Council on Medical Ethics, celebrating its 30-year anniversary in Stockholm from 9-10 September 2015. We were invited to speak about how the ethical debate in the Danish Council on Ethics has changed in nature through the years since its establishment in 1987.
- The UNESCO 11th World Conference on Bioethics, Medical Ethics and Health Law in Naples, 20-22 October 2015. Here, ethics committees from around the world gathered to discuss relevant ethical issues.

THE COUNCIL ON THE WEB

Towards the end of 2015, we launched our new website. Demand for our material is increasing, especially from pupils and students, who use it for the various projects they work on.

Our new website is organised by themes, which makes our material easier to find than before. Under each theme, it is possible to search for the Council's statements, reports, news or educational material.

We pay attention to the fact that many of the topics we work with are complex to learn. This is why we strive to use clear and explicit terms while prioritising the use of other media such as video, graphics and imagery to support our communication.

On [Twitter](#) and in our newsletters, we provide regular updates about the work of the Council and the debates we join.

Research with health data and biological material in Denmark

Combined, the biotechnology revolution and advances in digitisation mean that massive volumes of health data are being collected and made available in data registries and biobanks. It is widely held that the Danish collections of data and tissues have great potential to strengthen Danish research, treatment services and social economic growth.

But the emergence of recent cases about data leakage and misuse reminds us of the importance to build and maintain a research environment that will promote continued public support for research and healthcare services. Digitisation has made the number of data breaches grow.

Health data could hold particularly sensitive information about an individual's present, past and future health problems. It could be a violation of privacy – potentially leading to discrimination and stigmatization – if errors are made and data are leaked. The population's trust in research and the healthcare system could be damaged as well.

During 2014-2015, we have investigated the ethical dilemmas that have followed in the wake of this development. We have looked

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We recommend greater openness about and control of the comprehensive collections of health data and tissues originating from the Danish population in the form of blood samples and genetic data.

into how society, given today's circumstances, should balance various concerns focusing on the values of solidarity, benefit, privacy, trust and self-determination – asking the following questions:

- How should the privacy of citizens be protected?
- How should solidarity-based and efficient health research be promoted?
- How should citizens' trust in research be preserved?
- What role should the citizens' self-determination play?

The work is summarised in the statement Research with health data and biological material in Denmark, which was presented at a meeting at Christiansborg in May 2015. The statement is based on three background papers on the ethical, legal and factual aspects of research in health data. The statement is available in English and the background papers in Danish on our website: www.etiskraad.dk/english/publications, and www.etiskraad.dk/etiske-temaer/sundhedsdata.

In 2015, we participated in a number of debating events about health data: Chairman of the working group, Thomas Ploug, participated at meetings with the Strategic Alliance for Registries and Health Data, the Danish Medical Association, health political spokespersons from the Danish Parliament, Danish Regions, etc., and the topic was also discussed intensely at the people and politicians meeting 'Folkemødet' on Bornholm, see page 16.

READ MORE ON ETISKRAAD.DK

+ [Research with health data and biological material in Denmark](#)

Love child (Danish: Ønskebarn)

The use of new technology raises a complexity of ethical questions about having children. Love child is an educational material for elementary school, grades 8-10, about the choices to be made when children are brought into this world with help from technology.

The booklet gives the pupils knowledge about the ethical questions that come with the techniques used in human reproduction. While some of the techniques are already used in hospitals and clinics today, others are under way. Regardless of whether a technique is already used or being developed, attention should always be paid to ethical concerns when attempts are made to change the fundamentals of how life begins.

In the booklet, we meet a number of persons who in various ways have first-hand experience with assisted reproduction.

The pupils can read an interview with a woman who has chosen to become a 'solo mum' with donor sperm and tells us about the many considerations and thoughts behind deciding to have a child alone and about her daughter's future.

We also interviewed a fertility doctor who explains the possibilities for childless couples and single mothers to get help having

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There I was, recently divorced and with no luck on the dating market, and my biological clock was ticking at light speed. So, I told myself that I would do my very best as a mother, hoping that my daughter will be happy that I chose to bring her into this world.

— Signe Fjord, about her choice to become a solo mum

children. And we interviewed the CEO of the world’s largest sperm bank who tells us about the considerations behind offering sperm to childless people from both anonymous and non-anonymous donors.

With the booklet, we have also published a number of theme texts and videos that can be viewed on our website.

In 2015, Love child ranked among our most popular web content. We had 12,000 booklets printed, and they have now been distributed to the teachers who ordered them. The material is still available for download or printing from our website: www.etiskraad.dk/oenskebarn (in Danish only)



LOVE CHILD

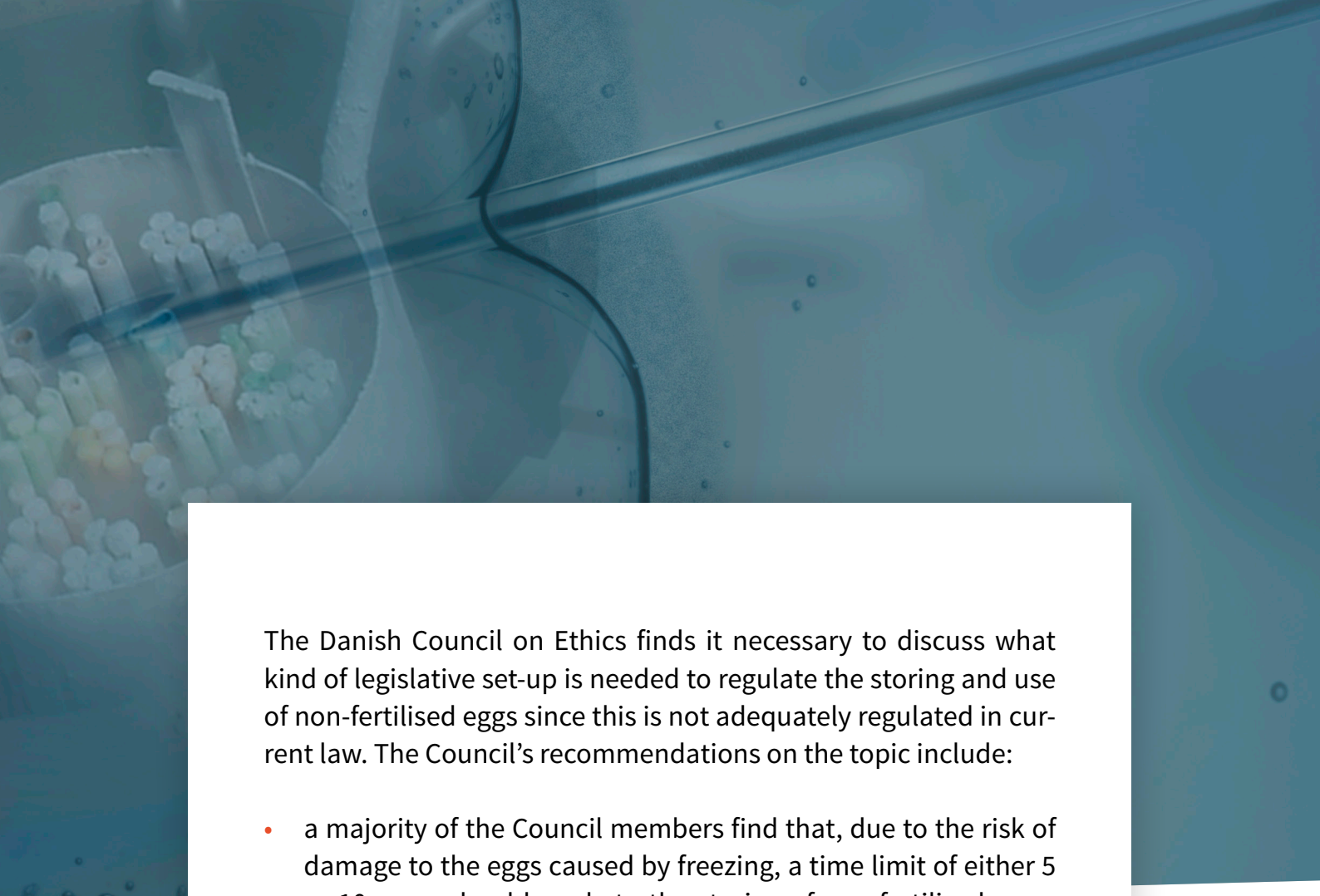
An educational booklet in Danish about the possibilities and dilemmas of reproductive technology
(Available in Danish only)

Storing and use of non-fertilised eggs

It has become possible to freeze non-fertilised eggs and use them in assisted reproduction at a later point in time. It has brought about new options, including the possibility for women to store their own eggs and use them later. It is relevant for women who are exposed to the risk of infertility as a result of having their eggs or ovaries removed due to illness and treatment, e.g. caused by cancer.

It could also be relevant for women who wish to 'prolong' their reproductive period. While these women are still fertile, fresh eggs can be removed for storing and use in assisted reproduction at a later point in time when these women would not be naturally fertile. The method can be used by women who, at an advanced age, have not yet met the man with whom they want to have children. It is first and foremost the woman's age at the time of egg removal that decides whether pregnancy is possible.

The possibility of freezing non-fertilised eggs also increases flexibility in connection with donation. The female recipient does not need to have the egg inserted on the same day it was removed; non-fertilised eggs can travel around the globe; and it is possible to establish 'egg banks' with descriptions of the donors as we know it from sperm banks, etc.



The Danish Council on Ethics finds it necessary to discuss what kind of legislative set-up is needed to regulate the storing and use of non-fertilised eggs since this is not adequately regulated in current law. The Council's recommendations on the topic include:

- a majority of the Council members find that, due to the risk of damage to the eggs caused by freezing, a time limit of either 5 or 10 years should apply to the storing of non-fertilised eggs. This time limit should be reviewed regularly in step with the collection of new evidence about the follow-on effects of freezing,
- a majority of the Council members, however, also find that there are other reasons – e.g. to encourage women not to have children at an advanced age – why a maximum storage period of 5 years is necessary, which is already stipulated in the current legislation. Some members find that it should be possible to extend the storage period if needed in case of serious illness,
- a majority of the Council members call to maintain the existing age limit in legal assisted reproduction of 45 years for the woman who is to give birth to the child.

The difficult choice – challenges for the ethical consumer

In the beginning of 2014, we formed a working group that has worked with the 'ethical consumer' phenomenon. The phenomenon can be considered as a form of 'the vote with the wallet' to address problems to which the political system has struggled to find effective solutions.

One prominent example is consumers who have started to take responsibility through climate-friendly actions in response to the current generations' destruction of natural reserves, depletion of non-renewable natural resources and warming of the climate at a pace that threatens to destroy the basis for the livelihoods of future generations.

While they indeed have good intentions the consumers who exercise ethical responsibility through their choice of food, it is a valid question if it is an efficient strategy to counter climate changes within the relatively narrow time window available before the current development has had irreversible consequences.

To gather inspiration for this work, the working group organised a debating event together with the Danish Agriculture & Food Council and the Danish Consumer Council on 17 November 2014.

Here, a line of experts met and contributed to answering this question. In the beginning of 2015, we published the anthology *The difficult choice – challenges for the ethical consumer* (in Danish only), which includes the speakers' contributions from the event.

In the spring of 2016, we will publish a report with specific recommendations. Follow us on our website: www.etiskraad.dk/etiske-temaer/natur-klima-og-foedevarer



THE DIFFICULT CHOICE

The anthology *The difficult choice – challenges for the ethical consumer* (in Danish only) includes 11 contributions from experts and stakeholders, each of them answering these questions from their own background.

People and politicians meeting 'Folkemødet' on Bornholm 2015

At this year's Folkemøde on Bornholm, we held a debating event on research in health data and biobanks. It is a topic that interests a lot of people, and the event attracted a full audience.

Several of the Council members were present at this and other debating events about euthanasia, welfare technology, data security, coercion in somatic treatment, food of the future, the climate, health equality and assisted reproduction, etc.

The short video clips below (in Danish) offer insight into some of the events we participated in.

PATIENTS WANT HEALTH, AND RESEARCHERS WANT DATA

Researchers collect health data about the Danish people on an unprecedented scale. It should benefit patients, research and society in general. However, the ethical dilemmas are sharper than ever. At his year's Folkemøde, the Danish Council on Ethics encouraged a debate about ethically sustainable solutions related to research with health data. In a tent with a full audience, participants met with representatives of the medical profession, researchers, politicians, the industry and the ethics sphere. [Watch video ▶](#)

IS THERE A FUTURE FOR THE CLIMATE COMMITMENT?

Is there a future for the climate commitment? COP21 in Paris is around the corner, however, given the experience from previous climate conferences, any major decisions should probably not be expected. Interview with Council member, Mickey Gjerris, and Head of Analysis in Cepos, Otto Brøns-Petersen, about why it is important to discuss the challenges facing us, and whether the climate commitment has a future. [Watch video ▶](#)

We will once again join the Folkemødet in 2016 with the following topics:

- + **THE ETHICAL CONSUMER** Does the individual consumer have a responsibility to curb climate changes, and what can the consumer do in that connection? The event will be held as informal and collective discussions between the attending audiences. First, we will give a brief account of the Council's activities, and then we will open a debate on consumer responsibility and potential initiatives. Further information in Danish is available at www.etiskraad.dk/etiskforbrug
- + **DIAGNOSES** Since the autumn of 2014, we have worked with ethical questions about the use of diagnoses, and this work was presented in January 2016. At the Folkemødet, we will participate in more debates with relevant participants. On our website, you can find more details about the project and see video footage from the announcement at Christiansborg (in Danish only): www.etiskraad.dk/diagnoser
- + **NUDGING AND PUBLIC HEALTH** The government, the regions and the municipalities all actively influence the Danish population's health behaviours – to the benefit of both society and the citizens. However, more and more people ask if the focus on health has made it so hard to be unhealthy in Denmark that the lives of many people are deteriorated? In 2016, we will be working on the project 'A friendly push?', and at the Folkemødet, we will join various events that put nudging and public health on the agenda. Read more about the project at www.etiskraad.dk/nudging (in Danish only)

BETTER TREATMENT – IN RETURN FOR MORE DATA

The EU Human Brain Project is to broaden our understanding of psychiatric disorders. To achieve this, large volumes of data held in European hospitals are needed. But when is it okay to use patients' personal data for research? Interview with Thomas Ploug, member of the Danish Council on Ethics, and Birgitte Kofod Olsen, Chairman of the Council of Digital Security, both of whom joined the debate. [Watch video ▶](#)

Consultation responses 2015

The Council has received a total of 18 consultation letters of which the below gave rise to elaborative responses (all links below are to Danish material):

- + 16 January 2015: [Response to consultation on draft bill to amend the Danish Executive Order on Interpreter Assistance Pursuant to the Danish Health Act](#)
- + 23 January 2015: [Contribution to evaluation of the Danish Health Authority's guideline on opting out of life-extending treatment, including resuscitation attempts, and on interruption of treatment outside hospitals](#)
- + 15 June 2015: [Response to consultation on draft bill to amend the Danish Executive Order on the Approval of Nationwide and Regional Clinical Quality Databases](#)
- + 31 July 2015: [Response to consultation on draft bill to amend executive orders and guidelines for the implementation of the amendment of the Act on Use of Coercion in Psychiatry](#)
- + 29 September 2015: [Response to consultation on the final reporting of the working group on pregnant women's abuse of intoxicants](#)
- + 8 October 2015: [Response to consultation on amendment of the Danish Health Act \(specification of delegation provisions, private emergency ambulance services, transport services, attendance fees, etc. to members of patient involvement boards, group of persons in health centres, etc., publication of enforcement of health-related requirements\)](#)
- + 8 October 2015: [Consultation on *The draft Additional Protocol to the Convention on Human Rights and Biomedicine*](#)
- + 23 October 2015: [Response to consultation on draft bill to amend the Danish Act on Assisted Reproduction](#)
- + 20 December 2015: [Response to consultation on draft bill to amend the Danish Health Act, Danish Act on the Right to Complain and Receive Compensation within the Health Service and Act on Authorisation of Healthcare Professionals and Healthcare Activities](#)

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.

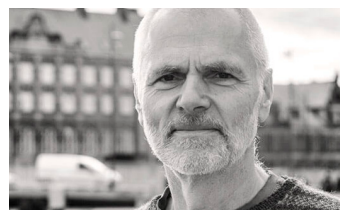
The Danish Minister for Health officially appoints the Council's members. When designating and appointing members, it must be ensured that both laypersons and specialists are represented, and that there is only one more of either sex than the other.

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

Members in 2015



JACOB BIRKLER
Chairman
MA, PhD
Associate Professor,
Teacher



GORM GREISEN
Vice-chair
MD
Clinical Professor,
Consultant



ANDERS RAAHAUGE
MA, Theologian
Cultural Journalist and
Parish Priest
(joined 21 August 2015)

Photo: Søren Kjeldgaard



CHRISTIAN B. STEEN
MA in Ethics and Values in
Organisations (MEVO)
Political Consultant

Photo: Trine Søndergaard



CHRISTINA WILSON
MA in Art History
Art Consultant



CHRISTOPHER ARZROUNI
MSc in Political Science
Debate Editor, Leader
Writer
(retired 8 July 2015)



JØRGEN CARLSEN
MA
Principal

Photo: Henrik Sørensen



KAREN STÆHR
Sector President, FOA
trade union

Photo: Hanne Paludan Kristensen



KIRSTEN HALSNÆS

PhD
Professor



LENE KATTRUP

Doctor of Veterinary
Medicine
Veterinarian



LILLIAN BONDO

Midwife, MPA
Chairman of the Danish
Association of Midwives



LISE VON SEELEN

Former Head of the
Rehabilitation Centre for
Torture Victims, Jutland
Former member of the
Danish Parliament



MICKEY GJERRIS

Master of Theology, PhD
Associate Professor



POUL JASZCZAK

MD
Consultant

Photo: Bente Jæger



SIGNE WENNEBERG

Writer, Lecturer



SIGNILD VALLGÅRDA

MA, MD
Professor



STEEN VALLENTIN

PhD
Associate Professor



THOMAS PLOUG

PhD
Professor

+ [See current members](#)

