

**33<sup>rd</sup> EUROPEAN CONFERENCE  
ON PHILOSOPHY OF MEDICINE AND HEALTH CARE  
7 – 10 August 2019**

**PHILOSOPHY AT THE EDGE OF MEDICINE**

PROGRAMME (DRAFT 13 MAY)

<b>Wednesday 7 August</b>	
16.00-18.00	<b>VENUE:</b> UNIVERSITY OF OSLO GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY MOLTKE MOES VEI 39
	<b>REGISTRATION</b>
18.00-18.15	<b>OPENING CEREMONY</b> SPEAKERS:  ROOM:
18.15-19.45	<b>Plenary panel 1:</b> SPEAKER PROF. LISA TESSMAN (+ PREPARED COMMENTARY): "Moral failure"  ROOM:
20.00	<b>WELCOME RECEPTION</b> VENUE

<b>Thursday 8 August (morning)</b>										
<b>VENUE: UNIVERSITY OF OSLO GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY MOLTKE MOES VEI 39</b>										
08.30-10.00	<b>Plenary panel 2:</b> SPEAKER: PROF. MARK KUCZEWSKI (+ PREPARED COMMENTARY): “Patient-centered practice – a view from philosophy” <i>Chair:</i> ROOM:									
10.00-10.30	BREAK									
	<b>Session 1.1</b> <b>Robotics, machine learning, &amp; big data</b> ROOM: <i>Chair:</i>	<b>Session 1.2</b> <b>Crisis &amp; trauma</b> ROOM: <i>Chair:</i>	<b>Session 1.3</b> <b>Reflections on medicine &amp; bioethics</b> ROOM: <i>Chair:</i>	<b>Session 1.4</b> <b>Professionalism</b> ROOM: <i>Chair:</i>	<b>Session 1.5</b> <b>Decisions at the end of life</b> ROOM: <i>Chair:</i>	<b>Session 1.6</b> <b>Mental health I</b> ROOM: <i>Chair:</i>	<b>Session 1.7</b> <b>Concepts of health &amp; disease</b> Room: <i>Chair</i>	<b>Session 1.8</b> <b>Clinical ethics &amp; medical decision making</b> ROOM: <i>Chair:</i>	<b>Session 1.9</b>  <b>Special seminar</b> (see below)  ROOM:	
10.30-10.55	<b>Considering AI/Machine Learning and Intellectual Resource Allocation</b> Robeson, Richard	<b>Responsibilities of Justice and Long-term Displacement: Ethical Place making and the Capability to be Healthy for Refugees and Migrants</b> Eckenwiler, Lisa	<b>Medicine at the Edge of Bioethics</b> King, Nancy M. P	<b>Is Professionalism Paternalistic? Reflections on the relation between professionalism and ethics</b> Arnason, Vilhjalmur	<b>Incorporation of the principle of the child’s best interest in end-of-life-decisions for infants</b> Klungland, Bahus Marianne	<b>Ethical trade-offs in Digital Phenotyping for Mental Health</b> Lyreskog, David M	<b>The need to clarify the concept of health among hospital leadership</b> Byrnes, Jeffrey	<b>The Role and Goal of Clinical Ethics Support Services: Patients and Charts?</b> Eijkholt, Marleen; Olsman, E		
11.00-11.25	<b>Digital Anthropology - Robotics and Artificial Intelligence in Medical Practice</b> Sahn, Stephan	<b>The Concept of Moral Injury: A Critique</b> Lang, Johanne; Schott, Robin May	<b>The roles of solidarity in Philosophy of Health Care</b> Puyol, Angel	<b>Ethical Climate for Healthcare Professionals: A Systematic Review</b> Hamada,Namiko	<b>Between the Individual and the Family: The Family’s Role in Decision making at the End of Life</b> Yakov, Gila; Samson, Tali	<b>Sensing mental health. The use(s) of sensor technologies in mental health care</b> Stokvik Lian, Hans Gunnar	<b>Work Health Ethics and Responsibilities</b> Müller, Sebastian; Kuhn, Eva; Buyx,Alena; Heidbrink, Ludger	<b>Ethical Counseling - the Next Step</b> Golan, Orit; Yakov, Gila		
11.30-11.55	<b>Pillo Health Digital Home Companion, Lowering Costs While Improving Outcomes</b> Osuji, Peter Ikechukwu	<b>Nightmares and the Ethics of Trauma Memory</b> Davies, Robert; Stoneham, Tom	<b>Perspectives from the Edges: The Power of Digital Narratives</b> Cline, Cheryl	<b>The moral challenges of mandatory vaccination; the case of Health Care Professionals (HCPs)</b> Damanaki, Maria; Gorantonaki, Anthoula	<b>Should patients with cognitive impairment be involved in advance care planning?</b> Sævarcid, Trygve Johannes Lereim	<b>Ethical challenges in outpatient commitment</b> Lovsletten, Maria	<b>Narrative Norms in Sickness: The physician as an exegete.</b> Del Fabbro, Olivier; Muller, Xavier	<b>Decision-Making Ability as Borderline: A Pedagogical Reconceptualization of a Legal and Medical Construct</b> Gibson, David		
12.00-12.25	<b>Beyond the four Vs. An exploration of researchers’ definition of Big Data</b> Favaretto, Maddalena; De Clercq, Eva; Elger, Bernice Simone	<b>The ethics of touch in a therapeutic relationship in physiotherapy</b> Przyluska-Fiszler, Alicja; Długolecka, Alicja; Rekowski, Witold	<b>Evidence-based medicine – a critical history</b> Louhiala, Pekka	<b>How have professional changes and cultural representations influenced the special status of the medical doctor within modern society?</b> Johnson, Rees	<b>Follow up on rejected euthanasia requests</b> Van de Vathorst, Suzanne; van den Ende, Caroline	<b>The dark side of care - Inadequate care, abuse and neglect in Norwegian mental health care</b> Husum, Tonje L; Nortvedt, P; Pedersen, R; Aasland, O	<b>Nietzsche and Holistic Health</b> McGarvey Timothy	<b>Best interests at the edge of medicine: The case of child protection interventions</b> Krutzinna, Jenny		
12.30-12.55	<b>Retaining Moral Responsibility in the Face of Medical Technology</b> Tigard, Daniel W	<b>Medical tourism – Palestinian / Israeli infertility treatments</b> Samara, Nivin; Barilan, Y M	<b>Physicians and retirement: why are retired persons often relegated to an “outlier” status in society?</b> Shandera, Wayne X		<b>The end at the beginning; consideration of end of life decision making in ventilator independent neonates with ultrashort gut syndrome’.</b> Peterson, Jennifer	<b>Barriers to family involvement in mental health care during severe mental illness.</b> Hansson, Kristiane M	<b>The patient’s everyday lifeworld. As a basis of the bioethical model of health</b> Pustovit, Svitlana; Palici, L; Boichenko, N; Berezina, V	<b>Reproductive Medicine in the United States, Women’s Rights, and the Ragged Edge of Legal Personhood for the Unborn</b> Nelson, Lawrence		
13.00-14.00	<b>LUNCH VENUE</b>									

Thursday  
8 August  
(morning)

VENUE:  
UNIVERSITY OF OSLO  
GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY  
MOLTKE MOES VEI 39

Session 1.9  
ROOM:

**Special seminar:  
New-old ethical perspectives on the development of prenatal testing practices**

*Chair: Christoph Rehmann-Sutter*

10.30-12.25

**Topic:** Mainly triggered by non-invasive testing (NIPT) for Trisomies 21, 13 and 18, and also by the prospect of more comprehensive easy prenatal genetic testing, the discussions on ethical issues around prenatal tests and diagnostic practices in different societies have again become very lively in the last few years. New regimes of screening and selection are emerging, formally based on the principle of reproductive autonomy.

Where are societies steering to? How is the inclusion of differently abled people in society connected with the moral issues of prenatal testing and selective abortion? What are the pressing societal issues of justice and injustice in relation to prenatal diagnosis? Which are the relevant ethical questions to ask?

This international Special Seminar is linked to an ongoing interdisciplinary comparative study between Germany and Israel. Its aim is to look at NIPT as a potentially disruptive technology in the context of prenatal diagnosis practices. The two countries Israel and Germany are known to take much different approaches to human genetics in general, and prenatal testing in particular. This will both highlight and re-align important categories and issues in reproductive genetics along several lines including:

- Moving health professionals and prospective users from the era of tentative pregnancy and moral pioneering to “non-deterministic counseling” and moral/translational gambling;
- Highlighting the considerable heterogeneity of views of parents of Down Syndrome children pro and con NIPT;
- Globally reducing as well as re-affirming cultural differences.

This opens an international space for empirically informed bioethical discussions also about other countries' prenatal diagnostic and prenatal selection practices. And it is a basis for raising the very fundamental philosophical questions that are implied in them. The special seminar consists of five 15 minutes input talks and an open roundtable where the audience can participate.

**Contributions:**

- Tamar Nov Klaiman (Ben Gurion University Be'er Sheva, Israel):  
“Attitudes of Israeli Parents of Children with Down Syndrome towards Non-Invasive Prenatal Testing and the Scope of Prenatal Screening”
- Stefan Reinsch & Christoph Rehmann-Sutter (University of Lübeck, Germany):  
“Women’s views on the normative dimension of health insurance coverage for NIPT”
- Vardit Ravitsky (Université de Montréal, Canada):  
“Non-Invasive Prenatal Whole Genome Sequencing: ethical and regulatory implications for post-birth access to information”
- Aviad Raz & Yael Hashiloni-Dolev (Ben Gurion University Be'er Sheva, Israel):  
“Pandora’s Pregnancy”. NIPT (as well as chromosomal microarray analysis and whole genome sequencing) – A new era for prenatal genetic testing”
- Hannes Foth & Christina Schües (University of Lübeck, Germany):  
“Prenatal genetic diagnosis and the conditions of childhood”

<p><b>Thursday 8 August (afternoon)</b></p> <p style="text-align: center;"><b>VENUE: UNIVERSITY OF OSLO GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY MOLTKE MOES VEI 39</b></p>									
14.00-15.25	<p style="text-align: center;"><b>Plenary panel 3:</b> SPEAKER: PROF. REIDUN FØRDE (+ PREPARED COMMENTARY): “Clinical ethics - at the edge of medicine and philosophy” <i>Chair:</i> ROOM:</p>								
15.25-15.30	BREAK								
	<p><b>Session 2.1 Sensor &amp; monitoring technology</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.2 Research ethics I</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.3 Health insurance &amp; DTC testing</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.4 Involvement of patients, relatives, &amp; other parties</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.5 Violence</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.6 Mental health II</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.7 Precision &amp; prediction</b> ROOM: <i>Chair:</i></p>	<p><b>Session 2.8</b></p> <p><b>Special seminar (see below)</b></p> <p>Room:</p>	<p><b>Session 2.9</b></p> <p><b>Special seminar (see below)</b></p> <p>Room:</p>
15.30-15.55	<p><b>Medicine 4.0 – Development of a criteria matrix for the ethical assessment of health- related apps</b> Schmietow, Bettina; Lindinger, Georg</p>	<p><b>Incidental Findings in Pragmatic Clinical Trials: Ethics at the Margins of Practice</b> Sugarman, Jeremy et al.</p>	<p><b>Behaviour-based insurance models: a just allocation of resources?</b> Kuhn, Eva; Buyx, Alena</p>	<p><b>Epistemic injustice in clinical ethics consultation</b> Holm, Søren</p>	<p><b>Promoting structural justice through mobile health technologies?</b> Sauerborn, Ela; Eisenhut, Katharina; Wild, Verina</p>	<p><b>On the edge of medicine: virtual companions and the curious case of sexual lethargy</b> Firth, Steven James</p>	<p><b>The precision paradox in personalized medicine: How can uncertainty be reduced when statistics do not apply?</b> Vogt, Henrik; Hofmann, Bjørn; Solbakk, Jan Helge</p>		
16.00-16.25	<p><b>Wearable and transparency strategies</b> Lorella Meola</p>	<p><b>. Harm, Responsibility, and Justice: How Well-Intended Political Considerations Overshadowed the Ethical Case against Animal Suffering</b> Häyry, Matti</p>	<p><b>Money for monitoring: the ethical challenges posed by data-sharing with health insurance apps</b> Martani, Andrea; Shaw, David; Elger, Bernice Simone</p>	<p><b>Patient involvement when facing severe mental illness and coercion - A qualitative study</b> Pedersen, Reidar</p>	<p><b>Developing and validating a novel index; doctor’s safety index that can aid hospital health policy to tackle the growing workplace violence against doctors.</b> Sankar, Gopi, Wahlang, Julie; Patowary, AJ; Wundawalli, Tej</p>	<p><b>Two perspectives on dual relationships</b> Unhjem, Jeanette Varpen</p>	<p><b>Organoid biobanking for precision medicine: stakeholder perspectives</b> Lensink, Michael A; Boers, Sarah N; Jongsma, Karin R; Bredenoord, Annelien L</p>		
16.30-16.55	<p><b>mHealth, self-management and empowerment: digital health technologies from a public health perspective</b> Hendl, Tereza</p>	<p><b>The Wives of the Tuskegee Study: An Untold History</b> Otero-Bell, RayLee</p>	<p><b>Regulations on Direct-to- Consumer Genetic Testing in Taiwan and China: Current Status and Problems</b> Liu, Hung-En</p>	<p><b>Participation in Clinical Decision-making Processes: Could a Human Rights- based Approach be helpful?</b> Hack, Caroline; Herler, Christoph</p>	<p><b>Whose Vulnerability? Rethinking the Violence Against Physicians</b> Hwang, Im Kyung; Lee, Soyoung; Noh, Dae Won</p>	<p><b>Unraveling the interplay of mental illness and treatment decision making: Implications for clinical ethics</b> Rushton, Cynda Hylton; Zwemer, Weare A</p>	<p><b>Predictive testing and diagnostic testing – a dubious dichotomy?</b> Starke, Georg; Shaw, David; Elger, Bernice</p>		
17.00-17.25		<p><b>The primacy of human being and the ethics of non- beneficial research</b> Rozynska, Joanna</p>	<p><b>DTC Genetic Testing vs Incidental Findings: Pros and Cons</b> Gefenas, Eugenijus; Lekstutiene, J</p>	<p><b>Digital health: Implications for the doctor-patient relationship</b> Amann, Julia; Vayena, Effy; Blasimme, Alessandro</p>		<p><b>Is self-expression through typing (SETT) a valid method of meaningful communication for minimally verbal (MNV) autistics?</b> Simonstein, Frida; Mashiach- Eizenberg, Michal; Cohen, Yael</p>	<p><b>Health technology and algorithmic fairness</b> Herlitz Anders</p>		
19:00	<p><b>Social programme</b> ...</p>								

Thursday  
8 August  
(afternoon)

VENUE:  
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Session 2.8  
ROOM:

**Special seminar:  
Communitarian bioethics**

*Chairs: Mark Kuczewski & Morten Magelssen*

15.30-17.25

**Topic:** Arguably, the communitarian tradition in ethics provides rich resources for bioethics which have for the most part been yet to be harnessed. This session will draw on communitarian thinkers such as MacIntyre, Walzer and Taylor in order to highlight areas where communitarian perspectives can enrich and expand the bioethical discourse. Such efforts will identify new pertinent topics, as well as pose critical questions to mainstream liberal bioethics. For many physicians, altruistic motivations for entering the profession have eroded, in part because health care as a social structure fails to create space for the type of moral community necessary to reflect on the meaning one might find in the practice of medicine. If medicine is a «practice» in the communitarian sense, what should follow – for professional identity formation in education, and for an account of the virtuous physician and a flourishing profession? Relatedly, a communitarian understanding of the ethos of clinical ethics can help us to identify and address social injustices such as the poor treatment of particular populations such as immigrant patients. Other examples that lend themselves well to illustrating central features of a communitarian approach are priority setting and rationing of care, and the balancing of autonomy and safety in home-based care. Finally, a critical communitarian analysis of modernity and moral philosophy, such as the one found in MacIntyre's works, can inspire a method of «deconstructive» analysis of normative work in bioethics. Central to this method would be the uncovering of implicit premises and presupposed accounts of practical rationality and the moral life, then showing how such presuppositions are problematic. The contention of the session is that communitarian perspectives can sometimes be much-needed correctives to bioethics performed within hegemonic liberal paradigms. This special session consists of three talks (20 mins each) followed by open discussion where the audience can participate.

**Contributions:**

- Morten Magelssen (University of Oslo, Norway):  
“MacIntyrean bioethics: Four applications in bioethics of Alasdair MacIntyre’s critical and constructive ethics”
- Mark Kuczewski (Loyola University Chicago, USA):  
“The practice of clinical ethics: Can it address social issues?”
- Michael McCarthy (Loyola University Chicago, USA):  
“Constructing Communities that Foster Physician Formation and Professional Identity”

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Session 2.9  
ROOM:

**Special seminar:  
Ethics of Global Health**

*Chair: Adnan Hyder*

15.30-17.25

**Topic:** Global Health has become an important topic in Bioethics in recent years due to its focus on worldwide health improvement by focusing on reduction of disparities, and protection against global threats that disregard national borders. Global health seeks to achieve this by emphasizing on problems that transcend national borders or have a global political and economic impact (Brown et al, 2006, Koplan et al, 2009). The success of global Health can be measured through reduction in prevalence of global diseases and mortality due to preventable causes and improvements in life expectancy globally (Bertram et al, 2018). The principle of global health justice has been used by others in assigning obligations and responsibilities in global health (Ruger, 2006: 2009; Widdows, 2015). In efforts to further strengthen discussions around Global Health Ethics, a proposal is hereby presented to offer a session on the Ethics of Global Health during the above Conference.

So far, inadequate philosophical and ethical attention has been paid to defining the ethical dimensions surrounding global health (Mills, 2011). As a result, there is a gap in the understanding of the ethical principles that apply to global health justice. The session will strengthen the roles of the various entities in the fight to combat the global health inequities by providing an opportunity to better understand the barriers, ethical issues and disadvantages that LMICs suffer. The session will additionally work as a platform for networking between different organizations, experts from different parts of the world and diverse specialties. The session will be instrumental in sensitizing participants on the ethical and moral issues around global health and in drawing the attention of current and future public health professionals. The specific goal of the session is to strengthen critical thinking on the ethics around Global Health in order to improve health justice globally. The session will promote exchange of ideas, encourage ethical and scientific debate and foster networking, partnerships and opportunities among experts from different clinical, research, and policy fields.

**Contributions:**

- Paul Ndebele (George Washington University, Washington DC, USA):  
“Global Health justice: The growth of the Global Health movement and the “one-healthy world Concept”
- Dr Endre Sandvik (Government, Norway):  
“Role of High Income Countries in Supporting Capacity and Access to health in low income countries”
- Speaker 3:  
“Improving access to new medical technologies for LMICs. OR The duty of care: Prevention and control of infectious diseases in poor countries”

<p style="text-align: center;"><b>Friday 9 August (morning)</b></p> <p style="text-align: center;"><b>VENUE: UNIVERSITY OF OSLO GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY MOLTKE MOES VEI 39</b></p>									
08.30-10.00	<p style="text-align: center;"><b>Plenary panel 4:</b> SPEAKER: PROF. SIGRID STERCKX (+ PREPARED COMMENTARY): “Medical end-of-life practices in Belgium - The good, the bad, and the ugly” <i>Chair:</i> ROOM:</p>								
10.00-10.30	<b>BREAK</b>								
	<p><b>Session 3.1</b> <b>Gene editing, gene drives</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.2</b> <b>Research ethics II</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.3</b> <b>Female genital mutilation &amp; male circumcision</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.4</b> <b>Oncology</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.5</b> <b>Geroethics &amp; dementia</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.6</b> <b>Donation &amp; transplantation</b> ROOM: <i>Chair:</i></p>	<p><b>Session 3.7</b> <b>Identity-related conditions</b> ROOM: <i>Chair:</i></p>		
10.30-10.55	A moral analysis of heritable human genome editing via CRISPR/Cas9 by He Jiankui Christian, Alexander	Checklist for applying to RECs: ethical and legal issues post GDPR Tzortzatos, Olga	The Ethics of Clitoris Transplantations: A Constructive Response to Female Genital Cutting Campo-Engelstein, Lisa	Cancer screening and the ethics of solidarity Reid, Lynette	Gerontological conceptions of ageing well and geroethics Ehni, Hans-Joerg	Anonymous donation in the ethics of transplant medicine Luków, Pawel	Body Modifications for Gender Expression and Why the Blurry Boundary between Health and Wellbeing May not Always Matter Murphy, Timothy F		
11.00-11.25	Germline gene therapy of sickle-cell disease and $\beta$ -thalassemia needs to change the gene therapy paradigm Sýkora, Peter; Chima, Sylvester C	Availability of post-trial access in clinical trials Jimenez, Edlyn B; et al	A case-based examination of obligations to reinstate female circumcision following childbirth in the United States VanDyke, Amy	Precision medicine and the fragmentation of solidarity Fleck, Leonard	Are we asking the right questions? Ethical issues of digitalization and new medical technology in care of the elderly Inthorn, Julia	What it means to respect a child’s agency in a no-choice situation. The case of bone marrow transplantation between siblings Rehmann-Sutter, Christoph	The (Un)Desirability of Difference: Theories of Health & Body Integrity Identity Disorder Gibson, Richard	<b>Session 3.8</b>	
11.30-11.55	An analysis of the ethics of human genome editing, grounded in African moral thought Behrens, Kevin	The Use of Homeless Populations in Phase 1 Clinical Trial: Is It Ethical? Kimbere-Zayas, Lisette	Two ways of belonging? Ritual circumcision of boys in liberal European democracies Solberg, Berge	Moving beyond the friend-foe myth. The use of social media in adolescent and young adult oncology De Clercq, Eva; Rost, Michael; Elger, Bernice	Dementia and the limits of health care Glos, Aleksandra	Sharing body material. The case of bone marrow transplantation between siblings Schües, Christina	Self-harm and autonomy. Some theoretical reflections on the diagnosis of borderline personality disorder Gelhaus, Petra	<b>Special seminar (see below)</b>	
12.00-12.25	Protecting the Best Interests of the Future Child in the Regulation of Gene Editing Technologies Mulligan, Andrea	Views and experiences of transcranial direct stimulation (tDCS) in children– findings from an interview study Sierawska, Anna	Ethics of pursuing targets in public health: the case of voluntary medical male circumcision programs in Western Kenya Rennie, Stuart et al.	Men’s repair work, care, and masculinity in the aftermath of prostate cancer treatment Brüggemann, Jelmer	Deciding on the use of biomarkers to estimate one’s risk to develop Alzheimer’s dementia: Applying the method of reflective equilibrium Smedinga, Marthe; Richard, Edo; Schermer, Maartje	Transplant ethics and cross border transplant abuse: The case of China Matas, David	Challenges in the Responsible Use of Digital technologies in patients with schizophrenia Chivilgina, Olga, Jotterand F, Elger B		
12.30-12.55	Crispr, Harm, and The Non-identity Problem Harrington, Olan Thomas	Lived experience of Hereditary Chronic Pancreatitis: between biographical contingency and biographical disruption Müller, Regina et al.	Revisiting traditional male initiation in South Africa. A global bioethical perspective Rheeder, Riaan AL	Reframing cancer Stenmarck, Mille Sofie; Engen, Caroline; Strand, Roger	Ethico-Political Aspects of Conceptualizing Screening: The Case of Dementia Gunnarson, Martin; Kapeller, Alexandra; Zeiler, Kristin				
13.00-14.00	<b>LUNCH VENUE</b>								

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Session 3.8  
ROOM:

**Special seminar:  
A Kodak moment? The effects of consumer genetics on medicine & society**

**Organizers:** Nordic Committee on Bioethics and the Norwegian Biotechnology Advisory Board  
*Chair:*

10.30-12.25

**Topic:** In 2017, a direct-to-consumer (DTC) genetic test was one of the top 5 best-selling products on Amazon.com during the Black Friday weekend. Genetic tests to learn about ancestry have become particularly popular. While sales are peaking, some unexpected effects of DTC genetic testing are beginning to surface. The biobanks of DTC companies have been accessed by the police on several occasions to solve cold cases. Anonymous sperm and egg donors have been found and contacted by their biological offspring. Children have discovered that their father is not their biological father.

DTC genetic tests also provide information about health. In the US, DTC genetic tests for Alzheimer's disease, heritable cancers and pharmacogenetics have been available since 2017 despite their controversial analytic and clinical validity. Broad use of such tests may affect the way we, as a society, think about health, disease, and responsibility for health. It may also create new demands on health care systems, clinicians, and patients. The regulations governing DTC genetic tests remain incomplete. In the US, DTC genetic tests were first introduced in the US market in 1996 partly due to a loophole in the legislation. In the EU, the IVD (In Vitro Diagnostics) directive regulates medical tests. However, in most European countries, genetic tests sold online fall outside of the scope of the legislation. In the Nordic countries, the debate on regulation is scarce and leaves many legal, ethical, medical, and philosophical questions unresolved.

This seminar will focus on main ethical questions raised by the use of DTC genetic tests:

- How does the use of DTC genetic tests affect our understanding of health and disease?
- What will the impact of DTC genetic tests be on the boundaries between established medical norms and values such as curiosity and the right to know?
- Are DTC tests a useful supplement to health care systems or an additional strain on already scarce resources?
- How will DTC genetic tests affect relationships between the state, individuals, and the public and the private sector?
- Is it possible and desirable to regulate or ban DTC genetic tests?

The organizers, the *Nordic Committee on Bioethics and the Norwegian Biotechnology Advisory Board*, collaborate with a well-established network of scholars, practitioners, patient organizations, and politicians.

**Contributions:**

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- ...
- ...

<p style="text-align: center;"> <b>Friday 9 August (afternoon)</b> </p> <p style="text-align: center;"> <b>VENUE: UNIVERSITY OF OSLO GEORG SVERDRUPS HUS – UNIVERSITY LIBRARY MOLTKE MOES VEI 39</b> </p>								
	<b>Session 4.1 Systemic issues</b> ROOM: Chair:	<b>Session 4.2 Enhancement I</b> ROOM: Chair:	<b>Session 4.3 Euthanasia &amp; suicide</b> ROOM: Chair:	<b>Session 4.4 Trust</b> ROOM: Chair:	<b>Session 4.5 Artificial intelligence</b> ROOM: Chair:	<b>Session 4.6 The limits of autonomy</b> ROOM: Chair:	<b>Session 4.7 Priority setting &amp; responsibility</b> ROOM: Chair:	
14.00-14.25	<b>Institutional Racism and Prevention of use of Alcohol and other Drugs: A Bioethical Reflection</b> Leite Ribeiro, Andréa; Wanderson, Flor do Nascimento	<b>Maybe she's born with it, maybe it's epigenetics: Cosmetic enhancement and fight against lookism</b> Räsänen, Joonas	<b>The borderline between suicide and medical aid-in-dying</b> Margaret Battin	<b>The Fragility of Patient-Trust</b> Spear, Andrew	<b>AI – Giving medicine an edge and pushing privacy to its edge</b> Bentzen, Heidi Beate	<b>What does autonomy mean in a clinical setting?</b> Sahm, Antonia	<b>Priority setting in primary health care – a qualitative study on allocation of nursing home placements</b> Heggstad, Anne Kari Tolo; Forde, Reidun	<b>Session 4.8</b>  <b>Special seminar</b> (see below)  ROOM:
14.30-14.55	<b>Choice, Health and Reason of State</b> Anastasya Manuilova	<b>Are we designing now or what?</b> Segers, Seppe	<b>Is suicide tourism a moral phenomenon?</b> Sperling, Daniel	<b>Trust in Patienthood</b> Kiran, Asle H	<b>Human intelligence and artificial intelligence: which cooperation and ethical implications?</b> Pegoraro, Renzo; Benanti, Paolo	<b>Is a more paternalistic framework needed to respect and enhance participant's autonomy? The challenge of electronic informed consent</b> Lõuk, Kristi	<b>Severity and priority setting in health care – setting a challenging research agenda</b> Barra, Mathias et al.	
15.00-15.25	<b>Who Is Responsible for the Care Crisis in Modern Medicine?</b> Khalili, Mahdi; Babeii, Saeedeh	<b>CRISPR, CCR5 and the Chinese Twins: does scientific progress sometimes require unethical practice?</b> Gunson, Darryl	<b>There is no morally relevant distinction between active and passive euthanasia</b> Guerrero, Jose	<b>Personalized (PM) medicine, expertise and trust</b> Myskja, Bjørn K; Steinsbekk, Kristin S	<b>Using AI for diagnostic purposes in health care: ethical implications</b> Helgesson, Gert	<b>Surrogacy as a practice of autonomy – an attempt to formulate a practical concept</b> Korbacz, Katarzyna	<b>The Possibility of Collective Needs</b> Gustavsson, Erik	
15.30-15.55	<b>Strategic determinism: public communication of the Estonian biobank</b> Seppel, Külliki	<b>The medicalization of appearance</b> Pahle, Andreas Saxlund; Vogt, Henrik	<b>To let Die or not to let Die? Decision making, Medical Practice and Court Rulings in Light of the Dying Patient Act in Israel</b> Zuckerman, Shlomit	<b>Trust, death, and suspicious circumstances - a 21<sup>st</sup> century Jekyll &amp; Hyde case?</b> Schmidt, Kurt W		<b>Neuroadministrative devices and personal autonomy.</b> Odorčák, Juraj	<b>Personal responsibility for health is a futile project</b> Ahola-Launonen, Johanna	
16.00-16.25		<b>Metaphysical Realism as a Cure for Chronic Cases of Medical-Ethical Fuzziness</b> Mosteller, Tim		<b>Medicine and human evil</b> Nortvedt, Per		<b>Medical Ethics and Value-Neutrality: The Troubled Relation Between Anorexia and the English Law</b> Condo, Jacopo	<b>Ethical accountability of decisions-makers in health: Readdressing power, risk and autonomy to promote trust</b> Baroe, Kristine	
16.30-17.00	BREAK							
17.00-18.00	ESPMH GENERAL ASSEMBLY ROOM:							
19.00-23.00	CONFERENCE DINNER "Eckbo" SELSKAPSKOKALER AS, JEGERVEIEN 4, OSLO							

Friday  
29 August  
(afternoon)

VENUE:  
UNIVERSITY OF OSLO  
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Session 4.8  
ROOM:

**Special seminar:  
Medical indication & medical practice – philosophy of a neglected concept**

*Chair:*

14.00-15.55

**Topic:** The notion of medical indication represents a cornerstone of medical practice. It is obvious that any medical indication contains a significant element of evaluation. It is not surprising that this fact is the cause of ethical challenges. In a way the concept entails a hidden agenda: who has the power in medicine? Ideas about appropriate medical acts and interventions may differ: between patients and physicians; between one physician and another. What are the values physicians source from when placing an indication? The concept of medical indication may be seen as an evaluative link between diagnosis and treatment. Where is the place in medical practice to give an account of the evaluative elements included in any indication placed? To place an indication is held to be a prerogative accorded to physicians only. Yet, what are the limits of power physicians are equipped with? Looking into medical practice the hidden tension and conflicts associated with the concept of medical indication come to light. They may be identified easily in many circumstances. E.g. if a decision has to be made to limit medical interventions such as cardio-pulmonary resuscitation. Should physicians follow their clinical judgement, or should they obey patients' wishes all the times even if outcomes will be disastrous? ("Is there such a thing as "fake resuscitation" or "slow code" interventions)? Similar problems arise for instance in the field of neonatal care. What is the indication to start intensive and lifesaving treatments in premature babies? How is the decision to be made if conflicts arise with parents? It would be easy to continue the row of similar conflicts arising in clinical care. It may be held that there is an obligation of the medical profession to disclose "indication policies". Surprisingly the concept has never been elaborated despite being a cornerstone of philosophy of medicine. In this seminar the concept of medical indication will be scrutinized from various perspectives:

**Contributions:**

- Michal Stanak:  
"Ethic of nudging in neonatal care"
- Ana Borovecki:  
"Medical indication and the perspective of public health"
- Stephan Sahn:  
"Medical indication and limiting life sustaining treatments"
- William Stempsey (College of the Holy Cross, MA, USA):  
"Indication Creep and Covert Values"

**VENUE:  
UNIVERSITY OF OSLO  
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MOLTKE MOES VEI 39**

**Saturday  
10 August  
(morning)**

**Plenary panel 5:**  
SPEAKER: PROF. BJØRN HOFMANN (+ PREPARED COMMENTARY):  
“Balancing on the edges of medicine: What is the role of ethics and philosophy?”  
Chair:  
ROOM:

**BREAK**

	<b>Session 5.1 Mothers &amp; embryos</b> Room: Chair:	<b>Session 5.2 Enhancement II</b> ROOM: Chair:	<b>Session 5.3 Genomics &amp; reproductive medicine</b> ROOM: Chair:	<b>Session 5.4 Death &amp; the brain</b> ROOM: Chair:	<b>Session 5.5 Global bioethics</b> ROOM: Chair:	<b>Session 5.6 Dilemmas, failure &amp; residue</b> ROOM: Chair:	<b>Session 5.7 Suffering &amp; pain</b> ROOM: Chair:	
08.30-10.00								
10.00-10.30								
10.30-10.55	<b>Maternal-fetal surgery: A challenge to existing notions?</b> Begovic, Dunja	<b>Cognitive enhancement defined as a function of identity</b> Rogers, Julie; Havyer, Rachel	<b>Ethical Challenges in Genomic Approaches to Infectious Disease: The Case of Phylogenetic Tuberculosis Sequencing</b> Juengst, Eric	<b>Are Organ Donors Really Dead? Brain Death and Personal Identity</b> Meier, Lukas	<b>Providing Content for the Human Right to Health</b> Gunderson, Martin	<b>The excess of empathy or why we can't resolve moral dilemmas with good intentions only. The case of Victor and the perverse strategy of pharma company Alexion</b> Devisch, Ignaas	<b>Medicalization of Chronic Pain</b> Stempsey, William	<b>Session 5.8</b>  <b>Special seminar</b> (see below)  ROOM:
11.00-11.25	<b>Potentiality, Futures of Value, and Abortion</b> Lizza, John P	<b>Genetically modified primates in neuroscience</b> Armason, Gardar	<b>In vitro gametogenesis: The end of egg donation?</b> Carter-Walshaw, Sarah	<b>Moral status of the brain-dead patient: Defying the Dead Donor Rule</b> Zonenszain Laiter, Yael	<b>The Devils in the DALY: Evaluating disease burden in the Global Burden of Disease study</b> Solberg, Carl Tollef et al.	<b>Bullying, Harassment and Undermining in Medicine Through the Lenses of Moral Failure and Morality of Violence Theories</b> Weber, Alan S	<b>An Erotics of Pain</b> Edgar, Andrew	
11.30-11.55	<b>Beyond moral status: the reification of the human embryo</b> Smajdor, Anna	<b>For the Sake of Convenience? Implantable Microchips and the Future of Work</b> Lawrence, David	<b>Young women's perspective on social egg freezing, results of a pilot study on Italian university students</b> Caenazzo, Luciana; Tozzo Pamela	<b>Defining Premature Death</b> Sorheim, Preben; Gamlund, Espen; Solberg, Carl Tollef	<b>Addressing pollution from antibiotics production through institutional systems in high-income countries: ethical tensions and trade-offs</b> Malmqvist, Erik; Munthe, Christian	<b>When the moral equation does not add up – on the phenomenon of moral residue</b> Solbakk, Jan Helge; Michelsen, Øivind	<b>Descartes' Ghost at the End-of-Life: Phenomenology and the permissibility of assisted suicide in depression</b> Seniuk, Patrick	
12.00-12.25	<b>Against exceptionalism in healthcare decisions (when capacity is in doubt), and how to get rid of it.</b> Zawiła-Niedźwiecki, Jakub	<b>Capabilities and Genetic Enhancement in Sport</b> Neiders, Ivars	<b>Posthumous paternity</b> Katzenelson, Edna	<b>The case for psychophysical dualism</b> Ahlzén, Rolf	<b>Traditional Chinese Medicine and the new “Personalized Medicine” / P4</b> Barilan, Y Michael	<b>From Psychometrics to Ethics. A Challenge for Response shift in Health-Related Quality of Life</b> Orlandi, Martina	<b>To Die Well: The Phenomenology of Suffering and End of Life Ethics</b> Svenaesus, Fredrik	
12.30-12.55			<b>Nothing if not family? On the meaning of genetic connections</b> Cutas, Daniela			<b>Diagnostic Injustice</b> Mills, Georgie	<b>Natality between Philosophy and Medicine</b> Wuensch, Ana Miriam	
13.00-13.30	<b>CLOSING SESSION</b> ROOM:							

Saturday  
10 August  
(morning)

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Session 5.8  
ROOM:

**Special seminar:  
Professional Health Care Associations Reactions to Legalized Assisted Suicide & Euthanasia**

*Chair:*

10.30-12.25

**Topic:** In all jurisdictions where assisted suicide and/or euthanasia (AS/E) were legalized, the responsibility for these practices was assigned to physicians (and in rare cases other medical professionals). This assignment appears to have happened without significant critical reflection inside the professions involved, and with even less discussion among politicians and the public at large. Concurrent with – and more commonly subsequent to – this process, different professional health care associations have changed their own ethics positions in which involvement by their members in AS/E has been rejected, to positions in which such involvement is tolerated, permitted or even embraced. Not only are these changes generally a departure from a long held prohibitive stance, in some instances the change appears at odds with other core moral commitments of these professions. Examples of such paradoxical departures include suicide prevention professionals not opposing the legalization of assisted suicide; opponents of physician assistance in suicide opposing physician assistance with lethal executions; and some palliative care specialists insisting that AS/E is a form of palliative care contrary to earlier held convictions about the goals of palliative care.

The aim of this panel discussion with the audience is to explore the forces that are causing health care associations to abandon their traditional opposition to AS/E and embrace it, even when it appears to undermine other core moral convictions. We propose 4 short 10-15 min. presentations, followed by debate with the audience.

**Contributions:**

- Leslie Bennett (The Sage Colleges, Troy NY, USA):  
“The surprising silence of the American Occupational Therapy Association vis-à-vis the increasing demand for assisted suicide when life has lost meaning”
- Cynthia R. Hall (Florida A&M University College of Pharmacy and Pharmaceutical Sciences, USA):  
“What’s the big difference? The medicalization of assisted suicide and euthanasia vs. the medicalization of the death penalty”
- Linda Scheirton (Creighton University, Omaha NE, USA):  
“The response of the profession of pharmacy to legalized assisted suicide and euthanasia”
- Jos Welie (Creighton University, Omaha NE, USA):  
“The response of the WMA, AMA and other professional medical associations to the medicalization of assisted suicide and euthanasia”