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ABSTRACTS

The case for psychophysical dualism

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The scientific revolution of the 17th century resulted in a pressing enigma: If man belongs to nature and nature follows natural laws which work fully deterministically – how may freedom of will exist, and how can there be an inner world of thoughts and emotions? Descartes wanted to solve this challenge by postulating that there is an immaterial substance, *res cogitans,* the thinking soul, that connects with the physical body, *res extensa,* in the pineal gland. Descartes has been much ridiculed for this attempt, and almost all evils of our time have been projected onto what is commonly called "dualism". With the rapidly expanding neurosciences, there has appeared a monistic materialism, declaring that the mind is plainly an epiphenomenon of the workings of the brain and that our subjective experience of an inner world and of some degree of free choices and resulting responsibility is just an illusion. This ontological position has gained strength to the extent that any dualistic position is looked upon as blatantly naïve.
In this paper, I want to challenge this position. I will draw inspiration from Karl Popper´s and John Eccle´s by now around thirty years old book *The Self and its Brain,* as well as Swedish philosopher Helge Malmgren, who defends a moderately dualistic position. It will be shown that dualism in a better way pays respect to the absolutely fundamental sense among most people that they have an inner world and that they have some degree of freedom of choice in their lives.
Interactive dualism, however, has to accept that there is a fundamental enigma involved in the mind-body problem: How can mind work on matter (i.e. certain structures in the brain), so that not only the brain creates the mind, but also that the mind changes the state of the brain? The position that will be defended in this paper is that science needs to accept that this is inexplicable with the present state of science, but that it, as many scientific enigmas, may be explained with time. It will also be argued that no religiously or metaphysically based theories need to be involved in this. The workings of evolution and the idea of emergent properties offer promising roads towards this richer understanding of the relation between mind and matter.

Personal responsibility for health" is a futile project

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Healthcare costs are increasing, and chronic diseases have a significant role in these costs. Furthermore, there seems to be a strong correlation between certain lifestyles and the chronic diseases. Boosted by the political trend of *the responsibilization of the individual* currently taking place elsewhere in politics, the health discussion has come to debate whether individuals should be held accountable for their lifestyle's choices. Due to these premises, both the theoretical and applied discussion on health, justice, and prioritization currently navigate in the complex jungle of *both* holding individuals accountable *and* taking account the social determinants of health affecting health behaviour. This is mostly done by operating within the family of luck egalitarian theories.
In this paper, I argue that this discussion should be taken into another direction. The project of finding accurate models of holding individuals responsible for their health is theoretically interesting. However, the applications end up being moralistic, simplistic or ineffective in the non-ideal real life. The consequences of the proposed applications are doomed to be unfair and ineffective.

Even though luck egalitarian theories *per se* can survive criticisms of unfairness (because they can be formulated in pluralistic and holistic exceptions and nuanced excusing conditions), I argue that taking the theories into applied discussions end up merely contributing to the political trend of the responsibilization of the individual. The finely nuanced accounts of responsibility are too complex for popular understanding and the (usually) preferred end-states of public insurance and strong redistributive institutions are buried deep under layers of theory.
"Responsible" behaviour in general is not without problems. The literature discusses certain specific risky behaviours related to health standards. It might be a good thing that people acted, at least remotely, according to those standards. However, this usually requires resources of several kinds, namely, the social determinants of health. Therefore, if the goal is to pursue these certain healthy behaviours, the reasonable (fair and efficient) approach should be to enhance the abilities of persons to act "responsibly", that is, *response-ability.* In other words, this means enhancing people's ability to make their own "best" decisions, not "decisions" made under extensively restricted autonomy under circumstances of scarcity.

Digital health: Implications for the doctor-patient relationship

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Patient-centered care has become widely recognized as the golden standard in healthcare. In its essence, patient-centered care refers to care that respects and responds to individual patients' needs and preferences. It seeks to foster patient autonomy by equalizing knowledge and power asymmetries that have long characterized the doctor-patient relationship. A key component of patient-centered care is shared decision-making, which is deeply rooted in the principles of good clinical practice that emphasize the patient's right to know. Shared decision-making thus presupposes a collaborative exchange between clinician and patient to ensure that all available and relevant information is taken into consideration and that the potential risks and benefits of a particular course of action are made evident to the patient. This, in turn, implies that information is provided to patients in a transparent and accessible manner.
To date, research in the field of precision medicine and digital health has predominantly focused on ethical issues related to the collection, storage, and sharing of different types of data for analytical purposes. Only little is known about the clinical impact of introducing data-driven models into practice. In which cases does it make sense to rely on predictive models generated by data analytics? What effects will these new decision support systems have on the doctor-patient relationship and on the provision of care more generally? How can we ensure that patients retain the right to informed choice and control over medical decision-making rather than being subjected to algorithmic classificatory practices?
The present contribution centers around the notion of shared decision-making in digital healthcare to generate a better understanding of how the inherent values of patient-centered care, in general, and shared decision-making, in particular, can be aligned with the emerging opportunities offered by real-time data analytics. It seeks to illustrate some of the key challenges associated with this process and makes recommendations on how to address them.

Traditional Chinese Medicine and the new "Personalized Medicine" / P4

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The Human Genome Project heralded a new vision of medicine, according to which, genetic and other "personal" markers would guide treatment as to render it more "precise". A broader vision, inspired by "system biology" speaks of the mobilization of IT in the processing of large amount of "personal data", from genomics to life-style as to "predict, prevent and personalize by means of participation".

This new vision embodies a turn to some metaphysical and regulative structures that were common in pre-modern Europe and most prominently in Traditional Chinese Medicine. Attention to these points may help us understand "personalized medicine" and some philosophical and moral problems it involves.

In the past (and still today), the poor availed themselves of "one drug fit all", buying remedies for problems from cheap providers. The rich consulted physicians who would write prescriptions for personalized mixtures of generic medicines. The very complex art of creating personalized concoctions renders it difficult to conduct clinical trials evaluating the effects of traditional Chinese herbology. It took a different paradigm of health and pharmacology to facilitate the development of "drugs that fit diseases" (rather than clinicians treat persons), and then test them in clinical trials.

The establishment of the Royal College of Physicians in 1518 England, marked the beginning of separation of physicians from apothecaries. During the centuries, it became illegal for physicians to sell drugs, especially medicine they personally develop and concoct. With the advent of P4, the problem of conflict of interest and of physicians' economic stakes in "personalized" care rears its head back.

Modern medicine relies on "big pharma" to develop drugs for the people. The economy of P4 is more dispersed, where numerous small "startup" companies vie for investment. The "Big Pharma" develop many drugs in parallel, while the new "startup" economy is about small companies whose stakes are limited to one technological breakthrough each, thus increasing risk of bias. The bias is double edged – in the face of patients, and in the face of investors.

Modern medicine has seen success that is based on reductionism to specific "pathologies". Traditional Chinese Medicine and P4 try to engross as many kinds of information about patients as possible. P4 counts on IT to validate its highly complex associations, but like TCM, it aspires towards an abstracted notion of "wellness" as a means to prevent and cure of particular disturbances or diseases.

Western medicine's turn to public health paved the way to social and political reforms, while oriental medicine's continuous focus on the patient as consumer, did not encourage the improvement of infrastructure and social institutions.

Genetically modified primates in neuroscience

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Because of their phylogenetic proximity to humans, non-human primates are an import animal model for many normal functions of the brain as well as brain disorders. The introduction of new genome editing technologies in primate research may enable studies of neurological disorders, such as Alzheimer's disease and Parkinson's disease, as well as psychiatric disorders including schizophrenia, depression, and anxiety disorders, in ways which are neither possible in rodent models nor in humans. Furthermore, the recent birth of two cloned cynomolgus

monkeys in China promises the possibility of producing significant numbers of genetically identical, genetically modified primates. The use of genome editing and cloning of nonhuman primates for research is already taking place. Early this year, the birth of five monkeys was reported, who are clones of a monkey that had been genetically modified with CRISPR to disturb their circadian rhythms. The creation of disease models in primates involves significant ethical problems, even more so when a large group of primates with certain neurological diseases is created. The disease may cause painful symptoms or harmful behavior, including self-harm. This presents ethical problems on its own, but also problems for husbandry and animal welfare. Genome editing in primates has not only the potential of creating new disease models, but also that of cognitive enhancement beyond what is typical for the species. Cognitive enhancement may come about deliberately or as a side effect of making the primate model of the brain more human-like, whether the purpose is to improve disease models or to study normal functions of the primate brain. If this leads to human-like characteristics that are relevant for personhood, the primates may deserve the moral protection of persons which in turn might makes such research morally indefensible.

The borderline between suicide and medical aid-in-dying

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A statement of the American Association of Suicidology issued in 2017 insists that "suicide" and "physician aid in dying" are not the same thing, although there may be overlap. A Canadian response holds that medical aid-in-dying (MAiD) is suicide, but the real issue is differentiating between suicides to be prevented and those to be facilitated. Other commentators ask whether VSED, voluntary stopping of eating and drinking, is suicide, and hence, whether it is legal or not, and whether interfering with attempts to do so is legal or not.
A report from Australia suggests that although suicide and assisted suicide are not legal, parliamentary, court, and other decisions are more lenient in terminal illness cases, suggesting that these phenomena are in fact viewed in different ways. Terms like "euthanasia," used in some (but not all) European contexts are anathema in other contexts, for example, the U.S..
Does language really matter? Using as its analytic strategy an attempt to distinguish between language that focuses on mechanisms and language that focuses on intentions, this study looks at a variety of "overlap" cases—for example, that of Robin Williams—to begin to map out the borderline between what is ordinarily called suicide and what is variously called physician assisted suicide, physician aid in dying, euthanasia, or MAiD.

Maternal-fetal surgery: A challenge to existing notions?

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Maternal-fetal surgery (MFS) encompasses a range of innovative procedures aiming to treat fetal illnesses and anomalies during pregnancy. This paper argues that MFS is highly ethically significant in that it compels us to reconsider our usual notions of maternal-fetal conflict and the relationship between the pregnant woman and the fetus. It also raises important issues with regard to respecting pregnant women's bodily integrity and autonomy. After discussing how our commonly used notions are challenged by the practice of MFS, I go on to suggest some ways of rethinking these concepts to make them more appropriate to this context.

Maternal-fetal conflict is usually thought to arise when pregnant women behave in ways that are potentially harmful to their fetuses, such as smoking during pregnancy. In the context of MFS, the conflict occurs if a woman refuses to undergo surgery despite prospects for fetal benefit. However, it remains unclear what exactly the conflict is about: is it a matter of conflicting maternal/fetal interests and needs, or simply a case of the pregnant woman endangering fetal well-being? These questions lead to the related issue of how to understand the maternal-fetal relationship. The main ways of conceptualizing this relationship are the two-patient and one-patient model. On the former, the fetus is recognized as a patient in its own right that can potentially have clinical interests distinct from those of the woman. On the latter, the pregnant woman is the only patient and the fetus is treated as her integral part. It is difficult to see how a maternal-fetal conflict could occur on the one-patient model, which is thus considered better suited for preserving women's autonomy and bodily integrity. On the other hand, the two-patient model is thought to 'erase' women from the debate on MFS, obscuring their interests and jeopardizing their autonomy. It therefore appears that the one-patient model should be preferred.
However, in the case of MFS this leads to some counterintuitive consequences. For instance, if the pregnant woman is the only patient, it would be expected that the procedure benefits her, but in fact it can cause significant physical harm. Without some kind of fetal patient in the picture, it would be difficult to judge the success of the intervention except in terms of maternal psychological benefits. Empirical research has also shown that women considering MFS see their fetus as a distinct entity, a future child that needs help. Yet it is important to be careful in invoking 'fetal interests', as this leads to the intractable debate about fetal personhood, potentially threatening women's reproductive freedom. I suggest that an ecosystem model, such as the 'maternal-fetal dyad' view proposed by Susan Mattingly, is best suited for upholding women's autonomy in MFS. However, this model would also need to incorporate some notion of fetal patienthood, such as the one proposed by Chervenak and McCullough, on which it is the woman's autonomous decision that makes the fetus as patient, but she is also free to withdraw this status.

An analysis of the ethics of human genome editing, grounded in African moral thought
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Human genome editing is an emerging technology fraught with complex ethical issues. Most of the existing literature dealing with these issues is grounded in familiar Western moral theories and principles. Very little attention has yet been given to the contribution that non-Western theories and value systems could make to the ongoing ethical discourse.
In this paper, I consider the ethics of human genome editing through the lens of African moral thought. I identify three salient African moral notions that may serve to enrich our ethical analysis of human genome editing.
The first of these notions is the wide-spread belief in Africa that all entities have a "life force" or "vital force" and that Illness and mental distress are often thought to be associated with a diminishment of the life force of the individual. The healing of body and mind can be achieved by restoring life force. Indeed, traditional practitioners often use parts of plants, animals and minerals to employ what is said to be their life force to bring healing. This way of thinking opens up the possibility of an acceptance of gene editing that is intended to heal or prevent illness. It would be no more playing god or acting against nature than many existing traditional healing practices are. If it is able to restore the life force of the sick, it is just another way

healing. Using our ingenuity to augment the waning life force of others is an intrinsically good act.
The second of these salient African moral notions relates to moral obligations to future generations. Western philosophers have struggled to give a coherent account of such obligations. Yet, by contrast, Kwasi Wiredu describes these obligations as the most "imperious" "of all the duties owed to the ancestors" This strong sense of obligations to posterity advises caution about proceeding with research and treatment using germline editing, at least until there is far more certainty about the effects on future people. However, notwithstanding the need for extreme caution, this same strong duty to posterity could, paradoxically, also provide moral justification for altering the germline in the interests of future generations. Provided we would be able to do so safely and with minimal risk of harm, surely if we had the ability to significantly reduce the incidence of many hereditary diseases, an "imperious duty" to future generations would compel us to do so.
The third African moral notion I appeal to is the preference for decision making by consensus over majoritarianism. The wisdom underlying this preference is that allowing all to have their say and continuing to engage until at least sufficient consensus is reached makes for better and sustainable choices. The lesson to the global community is that decisions about something that can affect the future of our entire species should be made in collaboration, and that we should seek to hear as many diverse voices as possible.

The surprising silence of the American Occupational Therapy Association vis-à-vis the increasing demand for assisted suicide when life has lost meaning
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Data from Oregon on PAS have made clear that consistently, the loss of meaning is one of the primary motives for patients to seek AS. A new bill in The Netherlands would allow AS for individuals who no longer believe their lives have meaning, even if they do not have any other medical condition making them eligible of AS/E under the current law. The core mission of occupational therapists (OT) is to help people with chronic and disabling conditions discover new meaning and purpose through engagement in occupations. Occupational therapists are uniquely qualified to address pain and other symptoms, and help find meaning and purpose, even at the end-of-life. However, there is evidence that patients with life-limiting conditions do not have adequate access to OT services to help them regain meaning. The profession is severely underrepresented in palliative and hospice care services. Paradoxically, many OTs advocate for the legalization of AS/E, possibly unaware about the incompatibility between the core mission of OT and the principal objective of AS/E. The world's largest professional association of OTs, the American Occupational Therapists Association, has so far abstained from taking an official position on AS/E.

AI – Giving medicine an edge and pushing privacy to its edge
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AI tools for assistance with medical diagnosis can be remarkable efficient. One example is facial image analysis for diagnosis of genetic disorders, which is so effective that it can even reveal information that cannot be picked up by experienced health personnel. However, such machine learning tools can be applied outside its intended context for other purposes, e.g. law

enforcement, and they can also be misused for discriminatory purposes – there have been media warnings that you can now be subject to genetic discrimination based on image analysis of your Facebook profile photo.
Legislation – in the European Union most notably the General Data Protection Regulation (GDPR) – creates a framework AI needs to operate within. The legal framework will be explained, and both its strengths and its shortcomings will be highlighted. Where are the gaps that need to be filled by ethics or law? Large corporations focus up on the importance of ethical AI: Is this merely a distraction to draw focus away from further legal regulations? What – if any – is and should be the role of ethics in the regulation of AI?

Medical indication and the perspective of public health
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Patients have preferences and wishes. They often make requests regarding they personal treatment preferences based on personal preferences, advice from other patients and family members, „fashionable“ medical trends, marketing of pharmaceutical industry, information they have seen on the internet.
They may request something from healthcare professionals but whether it is really based on their actual healthcare needs is often debatable. Whether their request can be transferred into medical indication remains to be explored within the physician patient relationship. Patient's requests may put strain on physician patient relationship in several ways. Firstly, patient's preferences may not always be based in evidence-based practices that healthcare professionals would like to promote and are often encouraged to promote by their healthcare institutions and healthcare systems in general. Secondly, patient preferences maybe based on new developments in the field of medicine, but the healthcare professionals may not be able to provide them with those services because of financial reasons within the healthcare systems or slow implementation of the new technologies in existing healthcare intuitions. Finally, patient's preferences maybe based on optimistic or pessimistic expectations, sometimes distorted ideas about one's existence which may put in question the goals of medicine and professional integrity of healthcare professionals. Issues of allocation of scarce medical resources, efficient and sound healthcare planning, and benefit for the individual vs. benefit of the healthcare system and other patients may arise. Also issues of implicit ethical values of healthcare system planning and evidence-based medicine may arise.
This contribution will try to explore all these issues.

Men's repair work, care, and masculinity in the aftermath of prostate cancer treatment
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The list of potential side-effects of prostate cancer treatment is long. Whether a man undergoes surgery or radiation, he usually experiences a loss of erection, weaker orgasms, sometimes incontinence, and more. In the current paper I use men's *repair work* (Persson, 2012) to study how men tackle these side-effects in their everyday lives, what trouble their repair work elicits, and with which masculinities the men negotiate. I view such repair work as part of men's care practices (Mol, 2008) and throughout the analysis of interviews with eleven Swedish men – all treated for prostate cancer – I show how such work is done with attendance to trouble with their bodies, selves, and others. Although some of this was done through formalized care and medical

technologies (erection injections and pills, diapers, sexual therapy), large areas of their repair work consisted of redefining their bodies, selves, and their relations to others. Some repair work was done within a couple relationship or collectively in-patient organizations, while for the most part the men were agents of their own repair. Within some of this *repair as care*, the men relied on traditional masculine norms and medical regimes, elicited in how they spoke of e.g. fixing and disciplining the body, risk-taking, or functional rehabilitation. But at the same time, this *repair as care* comprised a redefinition of or resistance against traditional masculine norms and the role of medical regimes, as illustrated in e.g. reformulations of sexuality and intimacy, collective sharing of vulnerability in patient groups, or embracing the "failing" body as the new normal. Such repair work lines up with what Nissen describes as *caring masculinities* (2017), which open up for care in ways often described as feminist; inherently relational, dependent, and emotional. I conclude the paper by teasing out some of the particularities of caring masculinities in the aftermath of prostate cancer treatment and discuss how attention to caring masculinities can inform debates about the boundaries of health care and patient hood.

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The need to clarify the concept of health among hospital leadership

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In addition to providing quality healthcare, the leadership of a hospital has the additional responsibility of creating polices and educating its staff. It is the supposition of this paper that all of these responsibilities require hospital leadership to have the best available conceptual understanding of their profession and role in the community. The importance of this connection can be seen in the way in which the problematic epochs of medical history were grounded in flawed understandings of the key concepts of medicine. Are our conceptual understandings of medicine better today? One metric for answering this question would be to investigate how often healthcare workers feel that their conceptual understandings are sufficient to allow them to understand what they are doing. Of course, healthcare workers feeling that they knew what to do in every case would not be a guarantee that the system they operate in was not draconian. On the other hand, if healthcare workers felt that they often 'didn't know what was the best path forward' might be understood as signaling a disconnect between their conceptual grounding and the job that they are being asked to do. Two recent studies by Rathert *et al.* and Houston *et al.* seem to indicate that the vast majority of cases do not leave caregivers confused about what to do. Thus, the majority of cases appear to be ones in which no intractable conflict arises among healthcare professionals and families— there is no breakdown. As desirable as this broad agreement is, it has two less desirable side-effects. First, this surface agreement covers-over substantially deeper rifts in the conceptions of health, as it is understood by the different parties. Secondly, the fact that agreement is so often reached without careful reflection can incline healthcare leadership to think that a conception of healthcare is *fully intuitive*. Occurring together, these two side effects can cause catastrophic breakdown. Even though Rathert *et al.* and Houston *et al* show that such cases of catastrophic breakdown are the minority, they are common enough that they too have become normalized. Practically, this

breakdown is often overcome by the exertion of power, typically one medical professional exerting power over another, or the medical institution exerting power over patients. The consequences of this exertion of power is also normalized as "just part of the moral distress of the job" or "just part of the struggle to participate in your own care". Yet, the frequent agreement in medical decisions should not lead us to ignore the weak conceptual foundations at work in many aspects of healthcare today. Here I argue that serious effort to work-out a conception of health is of the first importance among these conceptual foundations in need of clarification. Differing and incompatible conceptions of health are often the root cause of both instances breakdown in medical decision making, and the normalized stresses of medical care. This paper seeks to present the differing conceptions of health at work in contemporary healthcare, how they are the cause of some of the most intractable contemporary problems in healthcare, and the way in which continuing to suppress these differences exacerbates these problems. I close by suggesting ways this situation could be improved.

Young women's perspective on social egg freezing, results of a pilot study on Italian university students

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Fertility preservation is an emerging field that provides the opportunity to maintain reproductive health to all those people who either have to receive medical treatments or want to preserve their gametes to postpone childbearing (age-related fertility preservation). The majority of patients who can benefit from fertility preservation techniques are cancer patients. Until recently egg freezing was offered only for medical reasons, to women facing cancer treatments, or other fertility-impairing conditions, who had no other options for fertility preservation. This treatment is now commercialized from private centres, for non-medical reasons to healthy, ostensibly fertile women, who wish to postpone motherhood for various reasons such as educational or career demands, or because they had not yet found a partner. Today, social egg freezing means to preserve and store a woman's oocytes for non-medical purposes.
Due to the increasing demand for this procedure, some debated issues regard if it is reasonable to include social egg freezing in Public Healthcare System and consequently how to manage the storage of cryopreserved oocytes also from individual donors, how to support these egg banks and how to face, in the future, with the possibility that egg freezing will play a role in enabling childbearing for gays, lesbians, and unmarried persons.
In Italy, as in other countries, the procedure of oocyte cryopreservation is not specifically regulated, therefore, the referring normative has to be found in the law on Assisted Reproductive Technology (ART), given that, the collection and storage of oocytes can be justified from the perspective of their use at a later date by an appeal to ART.
With the aim to investigate attitudes, knowledge and intentions concerning social oocyte freezing among Italian young women, we have conducted a survey on a sample of 930 young female students of the University of Padova (Italy) on social egg freezing and their potential intentions regarding this procedure. Data collected in this study revealed some important points about young women awareness and knowledge about social oocyte freezing in Italy.
Our findings suggest that probably in our Country young women are scarcely aware that there is an age-related decline in fertility and that there is the possibility of using social egg freezing. In particular, they emphasize the fact that questions on social freezing are novel and timely in our Country and the medical community should be involved in debating and answering these questions in order to give young patients correct information about fertility and about the technical possibilities to preserve it and, eventually, defer childbearing.

In our country it is certainly necessary that a greater culture of knowledge of fertility is spread, even before in the female population, in the medical and scientific community, to encourage a process of informing young women by the health professionals concerned.

The Ethics of Clitoris Transplantations: A Constructive Response to Female Genital Cutting

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There has been much in the news lately about uterus transplantation for women without uteruses who wish to gestate a pregnancy and penis transplantation for men who have sustained genitourinary injuries. Critics of both of these transplantations claim that these surgeries are elective because they are not life-saving. However, proponents argue that these surgeries are restorative by allowing individuals to experience "normal" reproductive function (i.e. pregnancy for women and impregnating a woman via heterosexual intercourse). Moreover, since many people view their reproductive and sexual organs as symbolic of their gendered identity, these surgeries alleviate psychological distress associated with damaged gendered identities. Although I have not found any evidence of it in the literature, I am interested in exploring the idea of clitoris transplantation. Such a surgery could be used for women who have a clitoral injury or for women who have undergone female genital cutting (FGC). While clitoris transplantation will likely face many of the same objections as uterus transplantation and penis transplantation, it will surely face more given that it will not contribute to "normal" reproduction function. Yet clitoris transplantation would still be restoration—it would restore sexual function. With the increasing medical attention to female sexuality (dys)fucntion coupled with the continuing global advocacy against FGC, clitoris transplantation could serve as an option for women who underwent FGC as minors and now would like to experience full sexual function. Some may object that clitoris transplantation is not really functional, as women can still engage in sexual activity without a clitoris. Yet, an important component of sexual activity is pleasure, including orgasm, which may not be possible due to FGC. The standard of care for women with vaginal aplasia (i.e. an undeveloped vagina) is to create a neovagina for the purpose of "normal" sexual activity, which is presumabl vaginal-penile intercourse. At least in part because this surgery upholds dominant heteronormative values regarding sex, including that a woman must have an "accommodating" vagina in order to provide pleasure for her male partner, there has not been much pushback to these surgeries. However, there may be greater opposition to clitoris transplantation since the sole goal of this surgery would be to increase female sexual pleasure.

In vitro gametogenesis: The end of egg donation?

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In this presentation I will explore whether egg donation could still be ethically justified if in vitro gametogenesis (IVG) became reliable and safe. In order to do this, issues and concerns that might inform a patient's reasoning in choosing to use donor eggs instead of IVG are explored and assessed. It is concluded that egg donation would only be ethically justified in a narrow range of special cases given the (hypothetical) availability of IVG treatment and, further, that egg donation could itself be replaced by donation through IVG techniques. Two possible criticisms of this position are then considered: Ones based on respect for patient

wishes, and on loss of donor benefit. It is concluded that whilst neither argument constitutes a strong enough reason to continue with programmes of egg donation, egg-sharing programmes could still be permitted come the advent of IVG; these could then provide a morally acceptable source of "natural" donor eggs.

A moral analysis of heritable human genome editing via CRISPR/Cas9 by He Jiankui

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With the development of new methods for genome editing via CRISPR/Cas9 (Jinek et al. 2012), biomedical scientists now have tools for their research at their disposal, which are comparatively cost-efficient, widely available, as well as quick and easy in application. Although widely adopted in research as a means to produce genetically modified organisms, the application of these methods is also seen as ethically problematic, in particular in the context of human genome editing problematic (Baumann 2016; Brokowski & Adli 2019; Soniewicka 2018). It came as a collective shock for the biomedical and bioethical community when He Jiankui—a hitherto unknown biophysicist from the Southern University of Science and Technology in Shenzhen, China— announced in November 2018 that his research team had used CRISPR to deactivate the CCR5 gene in two human embryos (Normille 2018; Cohen 2018a, Cohen 2018b). Lulu and Nana are claimed to be the first two human beings with heritable genetic modifications. The modifications are the result of an experiment conducted to reduce the risk of HIV infections by deactivating a gene encoding a protein that enables the HIV virus to enter in human cells.

In this paper, I first provide a brief explanation of genome editing via CRISPR/Cas9 and a reconstruction of the events surrounding Jiankui's research. Then I conduct a moral analysis of this case differentiating (i) problems concerning good scientific practice (problems of comprehension, replicability, and reproducibility due to a lack of informational transparency, and active avoidance of regulatory authorities), (ii) problems concerning good medical practice (lack of informed consent, failed risk assessment concerning off target editing, genetic mosaicism, health risks due to deactivated CCR5 known in epidemiology (c.f. Cyranoski 2018), as well as the lack of health care provisions), and finally (iii) I discuss in what particular respects Jiankui's research was socially irresponsible. The analysis will confirm that the public outcry and universal rejection of Jiankui's research is justified. What is even more important from the perspective of ethics of science, the reaction to Jiankui's case is also a sign that scientific self-correction and self-regulation in biomedical research is actually working, but in some regions, institutional provisions are lacking which are necessary in order to prohibit actions by rogue scientists like Jiankui. The paper concludes with a series of recommendations focusing on the restriction of access to material that is necessary for using CRIPR/Cas9, and several approaches to foster informational and procedural transparency concerning the research with CRISPR/Cas9.

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Medical Ethics and Value-Neutrality: The Troubled Relation Between Anorexia and the English Law.

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In this paper I will try to understand why the value-neutral conception of autonomy endorsed by the Mental Capacity Act (MCA) – the Act of the Parliament of the UK related to the decisional capacity in medical context – is problematic in relation to patients with anorexia nervosa. First of all, I will analyse the model of autonomy advocated by the MCA and the procedures provided to apply the model in medical context. I will then illustrate the differences between the theoretical and practical approach to patients with anorexia (especially patients with egosyntonic symptoms), claiming that the practical procedure applied for them is biased and in contrast with the model. In the light of the model of autonomy endorsed by the MCA, indeed, patients with anorexia should generally be allowed to refuse medical treatment, but this is not what happens in practice. I will follow Simona Giordano's critique of the MCA claiming that this approach to patients with anorexia is discriminatory and contradictive, but I will not accept her conclusion about their decisional capacity. Reflecting on the model of autonomy endorsed by the MCA, Giordano makes the problematic – *brave,* in her words – claim for which patients with anorexia should generally be allowed to refuse treatment. I will claim that Giordano's *brave claim* cannot be considered the right option to resolve the dilemma of anorexics' refuse of force-feeding because it overtakes the preeminent problems exhibited by the law. Giordano's recourse to the *brave claim* is drastic and potentially harmful, especially if considered that scholars have developed – especially in the last two decades – broader and more fine-grained accounts of autonomy and human agency that could enable lawyers and health-care professionals to obtain a deeper insight on anorexics' decisional capacity without incurring in undesirable impasses. Both the defects of the practical approach of the MCA and of Giordano's *brave claim* are a clear sign of a deeper and more fine-grained error related to the value-neutral conception of autonomy in play. As the case of anorexic patients shows, impairments in decisional capacity cannot be understood without taking into account the values and reasons endorsed by the agency, but this procedure is hindered by the MCA's value-neutral conception of autonomy. Following Diana Meyers and Andrea Westlund, I will claim that values can be taken into account in the assessment of decisional capacity maintaining a neutral approach. Understanding that values are connected and able to interfere with autonomy does not necessarily imply a value-laden approach: certain values – as self-worth and self-esteem – "do not predict what autonomous people will choose to do or become other than being

autonomous"[1] Such values are not prescriptive, but they serve to frame the relation context in which the agency is embedded and the condition of existence and exercise of her autonomy.

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Nothing if not family? On the meaning of genetic connections

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The question of what implications genetic relatedness has for social or legal relations between people has preoccupied story-tellers, lawmakers, anthropologists, ethicists, and others, throughout human history. Reproductive technologies (especially those that involve reproductive material from people other than the intended parents), political borders (the crossing of which may be dependent on family ties), and the increasing popularity of DNA testing (which precipitates discoveries of mismatches between social and genetic relatedness), have intensified the need to clarify the interplay between different kinds of relatedness.
The relevant issue here has often been taken to be whether genetic relatedness is an essential ingredient of family relations. Families in which parents and children lack this dimension of relatedness have had much to worry about in terms of the social recognition of their bonds on a level equal to that of families which *are* so connected. However, if society were to stop looking at genetics to define family relations, would that imply that there is nothing left to say about such connections? If genetic relations are *not* family relations, does it follow that they are meaningless? We lack terminology to refer to genetic relations in language that is not family-based, which may contribute to the difficulty to distinguish between different kinds of contributions to children's lives.
In this talk, I explore the value of genetic connections beyond the family. I will review empirical work in which donor-conceived adults have pointed to non-familial needs to explain their interest in knowledge of and connecting with genetic relatives. I then contrast these accounts to the current tendency to express genetic connections as either family or nothing. If successful, this endeavour should contribute to reducing the tension that results from a conflation between claims to meaning of these different types of connections between people.

The moral challenges of mandatory vaccination; the case of Health Care Professionals (HCPs)

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Infectious diseases continue to pose a threat to public health in our days, even in the more economically developed countries. One of the most effective measures of modern medicine, in order to address the prevention of communicable diseases, is vaccination. Vaccines are undeniably linked to both individual and public health, thus creating a privileged field for the struggle of autonomy and freedom of choice against national immunization programmes. The role of Health Care Professionals (HCPs) is crucial in this fervent debate, not only due to their major professional contribution to the vaccination procedure, but also as subjects of vaccination themselves.
This presentation aims to investigate the ethical issues, the moral concerns and the possible moral justification regarding the mandatory vaccination of HCPs. What is the main reason that

HCPs choices are differentiated from the choices of other individuals regarding vaccination? Factors such as daily exposure in high-risk environments, direct contact with patients, the special doctor - patient relationship and the mission of HCPs inside public and private healthcare systems in general, are some of the topics that will be unfolded. Are the professional duties of HCPs compatible with abstaining from vaccination? How important is the contribution of the Hippocratic Oath in defining the professional duties of doctors in such cases? Furthermore, the presentation focuses on the way that the four bioethical principles of autonomy, non - maleficence, beneficence and justice apply to vaccination of HCPs. Last but not least, the authors examine possible solutions in terms of policy and legislation to tackle with cases where denial of vaccination from HCPs may endanger the lives of patients and other people in their working environment or undermine citizens' trust in the healthcare system.

Moving beyond the friend-foe myth. The use of social media in adolescent and young adult oncology

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Cancer is still the most common natural cause of death among adolescents and young adults (AYA). There is a growing awareness that AYA, who are maturing physically, cognitively and emotionally, are a unique population which should be treated by a multidisciplinary team. Although AYA tailored programs are emerging, in most countries they are unfortunately still rare or non-existent. As a result, AYA's needs and preferences are often underestimated as they fall in a kind of grey area between pediatric and adult oncology. Furthermore, studies reveal that available programs and services for AYA cancer patients are often not used due to lack of awareness and emphasize the need for more effective ways to deliver ("tailored") information. Given the extensive use of social media within this age group, it is important to explore how these technologies can be used to reduce the health disparity experienced by the AYA cancer population. Much has been written about the possible ethical and legal risks of the use of social media in healthcare – patient confidentiality, the privacy rights of colleagues, the credibility of the institution, the professionalism and the reputation of the healthcare provider, the professional and therapeutic relation between patient and provider, work-life balance etc. – but much less attention has been given to the myriad opportunities that these technologies can offer *both* for patients and healthcare providers and this across the cancer continuum, such as peer-support, legacy building, information seeking, networking, research opportunities etc.
The present presentation aims to encourage a conversation about the use of social media to improve patient-centred care in AYA oncology by discussing the results of a systematic literature review on AYA's and oncologists' attitudes on the emerging role of social media to provide high quality care within the AYA oncology context. The study results will be used to inform more focused best practice guidelines that will reduce oncologists' uncertainty about using these technologies. At present, most institutional and professional guidelines for the use of social media are written with expectations of misuse rather than with an eye on the many potential positive applications. It is important to move beyond the idea that social media are "foe" and focus on how we can use them in a fruitful way. Not doing so may negatively affect the care provided to the AYA cancer patient group.

Narrative Norms in Sickness: The physician as an exegete.

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Sickness establishes new conditions for the sick, to which he has to adapt. In other words, sickness sets new *norms* in the biography of the sick individual and exceed the definition of disease provided by medical science and become apparent in a different realm: that of narration. By referring to the works of the French philosopher of biology and medicine Georges Canguilhem, we will first explore the normative character set by sickness and the different forms of narration accompanying it, by looking at medical and general literature, in which individuals describe their personal perspective on being sick. By speaking, writing and reflecting on their personal experience with sickness, these forms of narration create a specific context, which is singular and cannot be generalized.
The consequence of narration is that the caregiver, e.g. the physician, is always confronted to an individual and not to an organ, cell or molecule. Thus, it is only by confronting the individual in a narrative process, that the physician is able to understand the *normal* and the *pathological* state, rather than focusing on a descriptive process of medical physiopathology. To illustrate this claim secondly, we will refer to articles in leading medical journals, where the physicians reflect on their own experiences with sick individuals in a narrative form.
In the last part, we will show how the confrontation of these narratives ultimately influences pragmatic actions, which in case of the physicians is medical therapy. It is our claim that before taking care of patients or even acting as an organ repairer, the physician has to be an *exegete* in order to interpret the patient's narration (c.f. Canguilhem, Writings on Medicine 2012, p. 50).
The argumentation presented in this proposal will finally raise the question of how modern medicine defines disease and if patients and physicians still *care* for individual narratives in therapy.

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

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In my book on empathy from 2017 (The excess of Empathy, De Bezige Bij, Amsterdam), I discussed the (dis-)advantages of empathy in society and in care. In a time in which social contrasts and social inequality are coming to the fore, there are loud calls for more empathy. From Barack Obama to Angela Merkel, many regard the human ability to put ourselves in another person's place as a driving force behind morality and a tried and tested remedy for indifference. Also, in healthcare, empathy is considered to be the key to take care of patients.
But is empathy always good? At the level of personal relationships, it is, but empathy is not a miracle cure that will solve all social problems and moral dilemmas. A degree of indifference is desirable, sometimes even a dire necessity. Empathy can also be misleading and is not a good instrument to solve moral dilemmas.
The question I would like to set in my paper are therefore as follows: have we perhaps forgotten why indifference can be useful and even necessary to keep society going? Of course, we need empathy. Indifference without any form of empathy is unworkable, but so is the opposite: a certain measure of indifference releases us from the impossible task of continually having to empathise with everyone in life. This indifference, if coupled with a government that aims to distribute its resources fairly, makes society workable. Only demands for more empathy offer no way forward.
Illustrating this with the case of Victor, at that time (2015) a boy of 9 years old, who suffers from an orphan disease and whose parents could not afford his medicine as it was no reimbursed at that time. As they cried for help in the media, the public opinion was very much in favour of

reimbursing the medicine and the minister of health was characterized as a cold and harsh woman. But when push came to shove, research revealed another story which has everything to do with the side-effects of empathy.

The Role and Goal of Clinical Ethics Support Services: Patients and Charts?

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Practices of clinical ethics support services in Europe seem quite different from those in the US context. Immersed in the clinical setting, US ethics consultants talk to patients and individual providers, go on rounds, immerse themselves in patients' medical records and offer recommendations that they write down in charts. Those features do not seem typical for ethics support services in European settings.
Some of these features of US consulting services can directly be explained by referencing to the roles and goals of ethics support services in the US. Literature about US services points describes three typical functions of clinical ethics committees - education, policy formation and consultation - and Rasmussen describes many roles of the consultant in US settings, including as an educator, facilitator, patient advocate and risk manager.
After experiencing the differences between EU and US practices, we have come to wonder: Which goals and roles do ethics support services have in European settings compared to the US, and could any role differences explain why practices differ? As ethics support services are developing in Europe, and the longer established US practices are undergoing standardization and professionalization movements, we wonder about the future of clinical ethics in Europe. Could we find any of these roles, as defined by US practices, to be desirable for integration in European settings, and if so, would we require a new definition of the roles of ethics services in the European context?
In our paper we set out the many roles of ethics consultants, as defined by Rasmussen, against the literature about ethics support services in European settings. By contrasting and comparing the roles of such services, we hope to identify if there is space to grow and develop European ethics services. We are particularly interested in the role of educator, which, in our opinion is one of the defining features of consulting in the US setting, and which requires patient participation and engagement with the medical chart. Is there a way to expand the roles and goals of ethics services in Europe?

The circle of hope and ethical challenges in clinical trials

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Today, biomedical research and care are closely intertwined and a public affair. Celebrities struck by cancer donate millions and raise funds. Scientists and pharma often proclaim new *breakthroughs, miracles and game-changers* in oncology. However, cancer research shows low success rates and most clinical trials do not reach the clinic. End-stage cancer patients often seek participation in Ph1 studies; unaware of the risks and minimal potential for treatment benefit. Sometimes they have unrealistic expectations and an inadequate understanding of trial purpose, the so-called *therapeutic misconception* [Study I].
Seeking suitable trials, patients increasingly search online for information, particularly common in the Nordic countries. There, public platforms provide descriptions of trials with the aim of helping patients find trials. We examined the Ph1 information given on the Nordic platforms

and found information quality highly variable and nearly all documents partly misleading. Additionally, the texts provided almost no information about possible adverse effects or disadvantages [II]. This highlight a communication problem and important ethical challenges. Therefore, we wanted to study the views of health care professionals and interviewed 68 nurses and physicians in the Nordic countries. We asked about challenges they encounter when including patients in clinical trials and what strategies, if any, they have to deal with ethical challenges.

Looking at nurses simultaneously caring for and doing research with cancer patients, we found that ethical challenges do arise. End-of-life patients presented the greatest difficulties; they are no longer responsive to standard therapy and eagerly volunteer for the cutting-edge drug trials in the hope of therapeutic benefit. Many nurses lacked systematic strategies for addressing such challenges but found support in colleagues and trusted research protocols to guide them ethically [III].

Strikingly, physicians downplayed the importance of ethical issues in their daily research work. They often found such challenges of no great concern. Reflecting over this, we find the existence of a 'culture of hope' a plausible explanation; the personnel and patients mutually uphold hope and support belief in the beneficial nature of clinical trials. As this culture is implicit in nature, efforts to make it manifest are imperative; then the constitutive characteristics become possible to discuss critically and, if necessary, further deliberated [IV].

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IV. Godskesen et al. The circle of hope and ethical challenges in clinical trials: A qualitative study in three Nordic countries of oncologists and hematologists' views. (submitted to *Medicine, Health Care and Philosophy*)

Beyond the four Vs. An exploration of researchers' definition of Big Data

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Big Data has been described by many as the buzzword of the decade. The term has been used pervasively in a broad range of contexts, both in academia and in industry, as an exciting new technology that will solve some of the world's most challenging problems in various sectors such as healthcare, climate change, criminology, and education. Traditionally described in terms of multiple dimensions, the so called Vs of Big Data, such as volume, velocity, variety, veracity etc., the term is currently used to describe a wide range of different concepts: from the capacity of collecting and aggregating vast amounts of data, to a plethora of advanced digital techniques designed with the aim of revealing patterns, trends and associations, related to human behavior. However, in spite of its widespread use, the term is still loaded with conceptual vagueness. The aim of the presentation is to explore the understanding of and attitudes towards the meaning of Big Data from the perspectives of researchers in Switzerland and the United States. For this purpose, a number of forty interviews were performed with Swiss and American

researchers involved in Big Data research in multiple disciplines. The study shows that researchers do not share a univocal definition of Big Data as most of the participants even admitted uncertainty towards expressing an opinion on the definition of the term. The traditional "V" definition was used, especially from researchers mostly involved in the development of algorithmic methodologies, however respondents could not agree on the number of dimensions to attribute to Big Data. Respondents also frequently associated the term Big Data to different concepts, such as the concept purpose – Big Data is data not collected for the purpose they are used for – and consent – Big Data is data collected without the knowledge or consent of the individual. Sometimes the term Big Data was also defined by the technical and methodological issues that it raises more than by affirmatives attributes – Big Data as data that is hard to handle or difficult to analyze. The study highlights how the lack of an overarching common definition of Big Data among researchers underlies the difficulty to univocally grasp the complexity of Big Data. The strong persistent association of Big Data with the challenges that it poses rather than with affirmative substantial characteristics further emphasizes such complexity. Although regrettably, an incongruous ongoing use of the term might jeopardize coherent development of research on this subject, the elaboration of a structured definition of Big Data might not be in the nature of the phenomenon.

On the edge of medicine: virtual companions and the curious case of sexual lethargy

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Despite evidence that global prosperity and social freedom are high, a marked decline in sexual activity has been noted in the U.S., Britain, Australia, and Japan. Though the cause of the decline is likely to be multi-faceted, sexual lethargy has been linked to increasing unhappiness — with some societies experiencing what has been described as "a mental health epidemic focused primarily around depression and anxiety disorders."[1]

Surveys reported in Japanese online magazines such as cocoloni.jp[2] indicate that 80 percent of Japanese women feel too tired to engage in romance — leading to the suggestion that exhaustion caused by long working hours and the resultant debilitating tension may be partly responsible for sexual lethargy. These findings are echoed by the Business Insider which notes that "…almost 70 percent of unmarried men and 60 percent of unmarried women are not in a relationship;"[3] the Japan Times goes further still and describes Japan as "Sexless" and notes that "almost half of all single young men and women are virgins."[4]

Yet, with 80 percent of respondents to a recent Japanese survey expressing a wish to settle down and find stability, the desire for companionship and marriage clearly remains.[5] Prompted by this unsated need for companionship, Gatebox has developed a virtual companion and "bride,"[6] Azuma/Aikuma Hikari. Marketed as a virtual bride with whom a person is able to share life and build memories, Azuma is technologically advanced and can interact with her partner visually, verbally, and through text; she can take part in activities such as watching television and cooking; and can operate smart-smart-home functions such as lighting, cooking, and heating. The holographic form of Azuma is that of Hatsune Miku (a Vocaloid — a computer-created voicebank and moe anthropomorph) and seems to be targeted at gynephilic individuals who seek to sate companionship needs rather than sexual needs. One such person, Akihito Kondo, was frustrated with the inability to meet real-life partners, and married Azuma in November 2018. In response to criticism of his marriage, Akihito remarked that "society pressures you to follow a certain formula for love, but it might not make you happy. I want people to be able to figure out what works for them."

Akihito's response raises interesting and provocative questions over the nature of future human romantic relationships, the role of sex in contemporary societies, and in the relationship between depression, sexual lethargy, and virtual companions. While there are, of course, many obvious ethical issues arising as a result of the current design and use of virtual companions, such technology seems to offer a solution to a societal need strongly linked to depression and sexual lethargy. In a world where human-to-human relationships are becoming harder to attain, it may be argued that virtual companions may help manage depression and anxiety brought about by isolation and being single. Accordingly, the development of virtual companions should be of interest to healthcare systems whose role it is to respond to issues of mental health.[7]

Footnotes:

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Precision medicine and the fragmentation of solidarity

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Solidarity is a fundamental social value in most European countries, though its precise practical and theoretical meaning is open to dispute. In a health care context, solidarity means roughly equal access to health care for all. It also means higher income groups will pay more health costs than lower income groups, and lower health risk groups will help pay the costs of higher health risk groups. Precision medicine includes 90 targeted cancer therapies with costs of €100,000 to €150,000 annually or for a course of treatment that will yield only extra months of life for a majority of metastatic cancer patients. CAR T-cell immunotherapy (for various leukemia's) has front-end costs of €450,000, and 30% of those patients will not survive another year. Can solidarity be sustained if (1) very high co-pays are required to access these drugs, or (2) these drugs are removed from a basic comprehensive benefit package and left to private insurance, or (3) cancers related to poor health behaviors (lung cancer and smoking) are not covered?

I argue that health care cost control is essential for preserving solidarity. However, the three mechanisms above are destructive of solidarity. What is needed instead are evidence-based, public, transparent, unbiased technology assessment organizations, such as NICE in the UK or IQWIG in Germany, that can motivate and educate broad deliberative processes from which would emerge a complex sense of health care justice that must be the core of a viable and stable

sense of solidarity. I illustrate what this would mean in practice with several concrete examples from precision medicine. In practice, a complex sense of health care justice will mean that the most we can reasonably hope to achieve is "rough justice" and "supple solidarity." The complexity, heterogeneity, and therapeutic uncertainty associated with health needs and related interventions guarantees the impossibility of achieving perfect health care justice. Further, as Rawls has noted, we are limited by the "burdens of judgment" and respect for "reasonable pluralism" in a liberal society, given reasonable (but conflicting) conceptions of health care justice. Those conflicting conceptions of health care justice also generate what policy analysts describe as "wicked problems." Consequently, a complex sense of health care justice and solidarity will require detailed "considered judgments of health care justice" connected to a range of specific clinical circumstances as opposed to broad, abstract principles of health care justice. Such judgments must emerge from fairly constructed, inclusive, rational and respectful processes of rational democratic deliberation through which just solidarity may be fashioned.

Prenatal genetic diagnosis and the conditions of childhood

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Since its introduction, prenatal genetic diagnosis was accompanied by reflexions about its potential to transform the structures of human relationships, in particular between parents and children. The possibilities to check the genetic dispositions of a foetus and, hence, to selectively abort it, presented new concerns and decisions for the expectant parents. The path of pregnancy and the way to a parent-child relationship is put under a particular biomedical surveillance by the society. Perhaps, children were never born truly unconditionally; however, today most children are born under the condition that they passed these examinations successfully. Therefore, we will discuss whether and how these conditions influence the child-parent relationship. When the child is born under the condition of a negative test result, will it have reasons to feel less love and care? Might the prenatal decisions of parents become an issue in the later relationship? Our discussion will also consider interview material from a comparative study about non-invasive prenatal diagnosis in Germany and Israel.

DTC Genetic Testing vs Incidental Findings: Pros and Cons

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The value of genetic information as well as policies dealing with the access to genetic testing and/or findings resulting from these tests have been one of the most intriguing ethical issues recently discussed both in the scientific literature as well as popular press. Direct to consumer genetic testing (DTC-GT) and incidental findings (IF) resulting from biobanking or genetic testing/screening have been the major themes for ethical controversies related to clinical utility, availability of pre- and post-test genetic counseling, the right to know or not to know the results of secondary findings, and privacy concerns. People buy DTC GT for two different reasons: to know about their ancestry as well as to get more information about their genetic risks and advice on disease prevention strategies. Despite numerous criticisms claiming that DTC-GT provides context unrelated data to not sufficiently informed customer - who is also exposed to privacy risks, it has been developing into a booming industry of services. On the other hand, a different kind of ethical debate has emerged in relation to a whole genome/exome sequencing (WGS/ES) introduced in biobanking, genetic testing and research. WGS combined with IF policies

promising return of the so-called "actionable" health related findings to those undergoing WGS, sparked the debate on "mandatory" return of IF as a benefit, which is available to those taking part in genetic research or biobanking. This paper aims to analyse main lines of ethical debate related to the mentioned practices providing information on genetic findings. An attempt will also be made to explore if market based and consumer rights driven spread of the DTC-GT that according to some authors has recently evolved into the so-called "DTC 2.0 model" can be counterbalanced by health care system developments based on policies introducing return of actionable IF in the context of biobanking, genetic testing and research.

Self-harm and autonomy. Some theoretical reflections on the diagnosis of „Borderline personality disorder"

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Autonomy is one of the central concepts in modern Western ethics, tightly connected to the ideals of Enlightenment and famously one of the four biomedical principles (Beauchamp and Childress).
As to the content of the concept, there are on-going controversies about how to understand it. In liberal traditions, it is often understood as „freedom from coercion" or „freedom of choice". In Kantian tradition it is more related to rational and moral decision-making in a long-time perspective of one's own best.
For all traditional meanings of "autonomy", severe psychiatric diseases and other forms of disturbed capacity to decide in a *normal* way are a challenge.
In my paper, I want to address a special kind of behaviour that can occur with certain psychiatric disorders, namely self-harm or self-injury. One of the most disturbing symptoms of e.g. Borderline personality syndrome is more or less severe and life-threatening self-injury.
Most Borderline patients have a history of trauma, abuse and/or neglect in their childhood. They have early (too early?) developed a seemingly functional side and manage to establish quickly intense but short-living relations. But they also suffer from an inner emptiness and low self-esteem that make them destroy the positive and constructive things that happen in their lives. It seems frustrating to accept the short- and long-term self-destructiveness as part of their identity and a matter of autonomous choice. Like in other diagnoses, psychiatry has gathered symptoms and criteria in order to describe the common problems (though each person is unique), in order to identify an addressable and possibly treatable disorder or disease. Still, it remains a problem how to respect the fundamental autonomy of a person who does not respect her- or himself. A relational concept of autonomy could help to understand better how the Borderline personality disorder has developed and in which ways it has corrupted the person who suffers from it.
An adequate, autonomy-focused therapeutic approach could build upon a relational theory of autonomy and use the therapeutic relationship in order to develop the patient's autonomy capacity in a more constructive, *healthy* way. In my presentation I want to elaborate some reflections on possible deeper relational aspects that distort the patient's capacity to act in a way that is compatible with her or his own best, and make good, free choices.

The Danish Council on Ethics recommendations about Genome Testing with focus on Direct to consumer genetic testing.

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Direct to consumer (DTC) genetic testing is a new option for healthy individuals where they are offered a genetic test by a private provider via the internet. Apparently, an increasing number of individuals are interested in DTC. Advantages with this approach includes a possibility for the individual to plan and take responsibility of her own health and some possible benefits to the health system economy. However, several difficulties exist, such as the lack of control with the technical quality of the analyses/data; lack of clinical validation and genetic counselling to the individual or relatives; misuse of the national health system when individuals request clinical follow up/screening for dubious test results; requests for prenatal diagnostics for conditions with only a mild clinical impact or for late onset disorders were prevention or cure is possible. But also data sharing/ownership or even selling the data to third parties without consent from the individual seems to be part of these issues.

Decision-Making Ability as Borderline: A Pedagogical Reconceptualization of a Legal and Medical Construct

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The belief that individuals can either have or lack the ability to make decisions is common. However the practice of classifying individuals according to such ability, is neither objective nor neutral. The Mental Capacity Act 2005 and the United Nations Convention on the Rights of Persons with Disabilities reify this everyday distinction, advocating for distinct legal responses to a cognitive conception of decision making inability.

Significantly both these discursive approaches can be framed as naturalising the idea of difference, and in response invoking rights based approaches (Minow 1990). An alternative approach frames the labelling of decision making ability as a relational practice reliant on narrative practices which serve to sanction particular forms of selfhood. Therein the legal discourses may be understood, not simply as responding to cases of decision making inability but rather as policing what counts as autonomous action, which is afforded protection from interference. The continued appeal to legal and medical discourses in the understanding and regulation of decision making poses a challenge to philosophical and bioethical thought in respect of how decision making ability should be understood conceptually.

A pedagogical conceptualization of decision making ability allows for the productive elements of legal and medical discourses to be acknowledged and responded to, in processes which privilege the relational space in which decision making ability is negotiated, performed, regulated and supported. On one level, an inability can be understood as a deficit which education can seek to ameliorate (Harris 1986). On a second level, an educational response can seek to foster resistance to dehumanizing practices, including legal discourses, and support the development or reclamation of freedom on the part of those considered lacking the ability to make decisions (Freire 1968).

The (Un)Desirability of Difference: Theories of Health & Body Integrity Identity Disorder

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People with Body Integrity Identity Disorder (BIID) seek to address a severe, non-delusional, incongruity between their internalised bodily-image and their physical embodiment, most commonly expressed as a desire to undergo an elective, healthy lower limb amputation. In short, they perceive themselves as being an impaired individual trapped within an unimpaired body.

The distress this incongruity causes can exist to such a degree that sufferers make attempts to amputate their unwanted limb themselves using methods such as dry ice, chainsaws, and lying in the path of oncoming trains. However, some surgeons have carried out healthy limb amputations for therapeutic need, to varying degrees of success. Unsurprisingly, the utilisation of healthy limb amputation as a therapeutic measure in BIID cases is considered, at best, ethically dubious; and, at worst, as the blatant breach of the principle of non-maleficence, and the irreversible bodily mutilation of a potentially mentally compromised patient.
Cases of BIID, and the unusual requests of those with the disorder, disrupt our practical and intuitive ideas about what the human form should look like and what is (un)desirable. Most people would not think twice about the ethical implications of moving an individual from a state of impairment to one of un-impairment. However, when this transition is inverted, moral and ethical debate abounds, specifically around the concepts of harm and autonomy. Arguably, this is because a desire to become 'physically impaired' seems drastically counter-intuitive.
This, in turn, leads to the following questions: is the elective amputation of a healthy limb, in cases of BIID, compatible with the purported goal of medicine; that of restoring and maintaining the health of an individual? Alternatively, do these procedures stand in stark contrast to the promotion of individual health? In essence, do these surgeries fall under the definition of health care? It is these questions which this paper will answer.
It will do this by employing a comparative analysis of biomedical and social models of health, illness, and disability; paying particular attention to Christopher Boorse's Biostatistical Theory of Health, and that laid out by Georges Canguilhem in *The Normal and the Pathological*. This analysis will investigate, and challenge, some of the foundational theoretical basis for such a one-directional way of thinking of appropriate 'transableism'. These theories will be used interrogate the basis for determining what an acceptable and unacceptable bodily form is. This paper makes a definitional distinction between impairment and disability, which, will allow for the therapeutic amputation of limbs in cases of BIID. The paper aims, to demonstrate that the intuitive appraisal of the results of amputation as incompatible with the definition of health can, in some specific cases, be inaccurate, and, that the voices of those with BIID can be used to challenge the consensus on what it is to be healthy.

Ethical Counseling - the Next Step
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As a result of changes in patient-doctor relations, accelerated technological development, and changes in the nature of medical treatment, new ethical challenges arise in the clinical field.
The therapeutic field is characterized by significant caseloads and ethical complexities. In addition, some of the staff members lack the tools to deal with ethical questions.
Over the years, health organizations have established frameworks for ethical counseling aimed at assisting health service providers in making decisions.
In Israel, ethical counseling exists in the health system as a result of legislation, and in addition, there is a voluntary ethical counseling framework. These frameworks do not provide a comprehensive response to clinical needs. Although these frameworks help address ethical questions, at the moment indices to examine successes are lacking.
In light of these shortcomings, we present a comprehensive model for ethical counseling which includes ethical standards based on a unique approach to ethics - Positive Ethics. This approach includes: training through field-based case studies, establishing ethical frameworks for staff, and ethical counseling. We seek to promote measurement of training and improvement of

ethical conduct. Identifying initial phases of improvement in the clinical field will encourage the system to invest more deeply in continued implementation of ethical frameworks.

Developing and validating a novel index; doctor's safety index (dsi) that can aid hospital health policy to tackle the growing workplace violence against doctors.

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Objectives: Aims to build an index; Doctor's Safety Index (DSI), a first of its kind in the world and including its value while developing health policy in a hospital so as to tackle the growing workplace violence against healthcare professionals which in turn can lead to better health outcome.
Methods: DSI is made with the variables that directly or indirectly affects or results in an environment prone to develop violence at a hospital level. Such variables were obtained from extensive literature review, sample surveys in healthcare practitioners, interview with victims of violence, opinion from legal medicine experts and hospital administration. Certain parameters are to be sampled from tertiary care hospitals.
Results: A preliminary index development is be made using the relevant variables mined by the foresaid methodology. Major variables that amalgamates into DSI of a hospital are 1- average violent episodes experienced by a doctor in the past one year, 2- Average waiting hours per patient, 3- Number of security persons per bed, 4- Established protocol for tackling violence, 5- Health insurance coverage, 6-Report rate of violent episodes , 7- Literacy rate, 8- Type of hospital, 9- Advanced payment requirements, 10-Average number of patients coming to the hospital in one year. The validation considered the relevance of normal distribution of points for report rate and literacy rate while combining the variables so as to avoid under reporting of violence episodes.
Recommendations: DSI of a hospital marks its status in the line of safety for its health professionals and make violence reporting mandatory irrespective of the severity. It creates an urge to improve status by policy changes. It is a baseline information for a doctor before joining a hospital and thus advantage of anticipation of problems and adds rewards for working in a hostile environment in future.

There is no morally relevant distinction between active and passive euthanasia

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In public debates it is common to use the notions of euthanasia, withdrawal of treatment and physician-assisted suicide (PAS) interchangeably. The expression 'withdrawal of treatment', rather than 'passive euthanasia' is frequently used to avoid public criticism. The idea of euthanasia has been so mistreated and misuse that people normally avoid its usage on the speech, to prevent that their contribution to the debate be directly unconsidered and regarded as an instance of active euthanasia, traditionally viewed as the intentional killing of an innocent human being and sanctioned as a morally condemnable action. However, following others like Rachels[1] and Buchanan[2], I do advocate for its broader and more appropriate use, including both instances of active and passive euthanasia, striping off all those layers of meaning that have inadequately been attached to it. There is no reason to believe that the term is morally charged with those negative features necessarily, but it simply is a morally neutral concept that will need further moral assessment when taking it to practice.

In this paper, I will first present an initial definition of euthanasia. Next, I consider some of its features to gain a more thorough understanding of this notion, as well as to being able to offer a strong defense of those cases where euthanasia is the morally acceptable and preferable action. There are two major classifications of euthanasia. The first one is based on voluntariness, ranging from explicit opposition to expressed consent and acceptance of the procedure. Within this spectrum we find three clearly distinctive types of euthanasia: 1) involuntary; 2) non-voluntary; and 3) voluntary. A second classification cuts across the first one to distinguish between different types of euthanasia based on the means employed to carry out the action: 1) passive, consistent in the withdrawal or withholding of medical treatment; and 2) active, where a lethal dose is injected to the person requesting it with the purpose of ending her/his life.
On its own, this latter classification does not directly address the supposed moral relevance of the distinction. Defenders of the distinction consider that letting someone die, i.e. passive euthanasia, is less morally blameworthy than a correspondent case of actively ending someone's life, i.e. active euthanasia. However, is there any morally relevant line to draw between active and passive euthanasia? I will argue that this is not the case, and the difference between active and passive euthanasia is exclusively an instrumental one, being the truly morally relevant matter the underlying moral assessment of the euthanasia cases, which renders the distinction inadequate. The rightness or wrongness depends on the merit of the justification underlying the action, not on whether it is an instance of killing or letting die, active or passive euthanasia. The relevant features to judge an instance are the actor's motive, the patient's preference, and the act's consequences[3].

Footnotes:

[1] Rachels, J. (1986). *The end of life*. Oxford: Oxford University Press.

[2] Buchanan, A. (1996). Intending death. In T. L. Beauchamp (Ed.), *Intending death: the ethics of assisted suicide and euthanasia*. Upper Saddle River, N.J.: Prentice-Hall.

[3] Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics*, Chapter 5. New York: Oxford University Press.

Providing Content for the Human Right to Health

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The human right to health is one of the fuzzier concepts at the edge of medicine and health care. Article 12 of the International Covenant on Economic, Social, and Cultural Rights provides that individuals have a right to "the highest attainable standard of physical and mental health." Realizing such an abstract right requires the provision of legally enforceable content. Under current human rights practice this is provided at the level of individual states. The Committee on Economic, Social, and Cultural Rights has offered guidance in General Comment 14 that sets out state obligations corresponding to the right to health, including minimum core obligations, but these guidelines are not legally binding in international law.
I argue that current human rights practice regarding the human right to health is inadequate. Realizing the human right to health requires strengthening international institutions to enable them to adopt global minimum standards that are legally enforceable through international adjudication. The role of the states is to apply the global minimum core standard in ways that take account of local conditions regarding disease burden and domestic values.
In the first section I review reasons for allowing states to determine the legal content of the human right to health. The reasons include respect for state sovereignty, the ability of states to take account of local conditions regarding disease burden and cultural values, and the feasibility of democratic participation in the design of national health policy. While these reasons are substantial, I argue that they are overridden by countervailing reasons. Human rights are

universal, and their realization requires ensuring equal access of all people to health resources that constitute a minimum standard of acceptable care. However, states with different levels of resources provide quite different health entitlements, and some states are not able to provide even a minimally adequate level of health care. In addition, states are not in a good position to cope individually with transnational threats to health such as climate change, the spread of pollutants, and pandemics.
In the second section I suggest a way in which current international law might be reformed in order to provide the legal content necessary to realize the human right to health. This requires reforming an institution such as the World Health Organization so that it can adopt enforceable international regulations regarding standards of adequate access to health-related resources and reforming international adjudication processes so that the regulations can be legally enforced when states fail to fulfill the human right to health. This does not mean that there is no role for individual states. The reasons given for allowing individual states to specify the legal content of the human right to health are best seen as reasons for allowing states leeway within the constraints of legally binding international health regulations.

CRISPR, CCR5 and the Chinese Twins: does scientific progress sometimes require unethical practice?

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Bioethicists have long been interested in the role that new technology may play in our lives; nothing captures the bioethical imagination quite like controversial biomedical developments, especially when the development takes us closer to the realisation of things that hitherto have only been discussed as hypothetical possibilities.
The recent announcement that the CRISPR/CAS9 technique has been used to create genetically modified twins - Lulu and Nana – is one such development. This paper will explore the significance of this development in light of previous debates about genetic enhancement, and governance arrangements. It is contended that, despite a history of many arguments about the ethical permissibility of genetic modification, the current orthodoxy is distilled down to a few core considerations. These are: safety, efficacy, and beneficial consequences. Other considerations such as social justice, and the wider social implications, whilst generating much discussion, have largely fallen by the wayside as strong ethical arguments.
The experiment which led to the birth of the twins is not only illegal in most countries, but it also fails the ethical tests suggested by the reduced core considerations: it is highly risky and possibly unsafe; we do not know if it will work; it is of dubious benefit as the embryos that were modified were not originally defective; simply put, the risk to the children is not justified because it is of no benefit to them, and could possibly be harmful. Given these core considerations, any desire to develop such research in humans is potentially impermissible because the risks will never be justified.
The paper considers the idea that in order for the genetic modification of human beings to become a reality, something unethical had to happen. It had to be tried in humans. This illustrates a central paradox of some forms of research: in order for a procedure to be ethically acceptable, it has to be tested in a way that does not meet current ethical standards. The experiments conducted by *He Jiankui* had to happen if 'proof of concept' was to be established. This is the beginning of the breakdown of the ethical objection that such techniques are too risky. Furthermore, we can expect that, once the dust has settled, teams of geneticists will be vying for access to the data harvested from the twins. We can expect, rather like the allied scientists at the end of the World War 2 encountering the results of the morally repugnant

experiments that had been conducted on patients, that current scientists will put aside their ethical reservations in the name of scientific progress.
This is rendered all the more likely by recent research showing that deleting the CR5 gene may also enhance cognition and memory. For the first time there are human beings, whose brains have been genetically modified, and from whom valuable research data could be harvested. The paper concludes with the view that the clamour for access to the data is likely to be even more intense once it is widely appreciated that there may be more modified babies.

The Possibility of Collective Needs
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Some people take needs to be conceptually linked to individuals rather than groups. However, it is not entirely clear why one should accept this view. There seem to be several cases where it makes better sense to understand the one(s) in need as a collective rather than as an individual. Consider a case of infertility in which there is a couple who cannot become pregnant. The doctor's recommendation is In Vitro Fertilization (IVF). To say that the woman involved needs treatment in order to become pregnant does not seem to quite capture what is going on. It may make better sense to say that the couple needs IVF *as a couple*. *They* need IVF in order to become pregnant. Whereas such an example may bring out the conceptual intuition it remains somewhat difficult to account for the moral implications, if any, for health care priority setting. One way to make sense of this case is to reconsider the assumption needs are conceptually linked to individuals rather than groups. In this talk I shall consider this possibility.

Participation in Clinical Decision-making Processes: Could a Human Rights-based Approach be helpful?
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The involvement of patients and relatives as well as the inclusion of different perspectives in the process of decision-making is – in theory – accepted as state of the art-policy in clinical practice. Respecting und strengthening the patients' autonomy should be self-evident. Still, the representation of different perspectives and the equal participation of patients are problematic, as we can see in our work in clinical ethics consultation. During the last years Medical Ethicists have discovered the human rights-based approach as another source for developing argumentations, for example by applying arguments from the *Convention of the United Nations on the rights of persons with disabilities* in different clinical contexts. With the distinction between 'impairment' and 'disabilities' it became visible, how a human-rights-based argumentation can change the discussion about participation to focusing the extinction of external barriers.
Could a human rights-based approach be helpful for the ethical evaluation of decision-making processes in clinical practice? Could it help to outline the importance of the integration of different perspectives? And – if so – what could substantially be added to an argumentation based on the principles of medical ethics? Should the right to participate in decision-making processes lead, consequentially, to institutional duties? For example the duty to create possibilities and provide means for everyone affected to *equally* take and be part of the process? Is this even possible?

As example, we would like to discuss the right to participation on micro- and meso-scale to examine if a human rights-based approach can not only be used for establishing governmental duties, but also for addressing individual or institutional rights and duties.
We will argue that the right to participation could be an addition to the principle of autonomy by Beauchamp and Childress. It allows a more differentiated, more substantial evaluation of this principle – especially by making a distinction between 'being part of' and 'participating in'. As it has been shown with the concepts of relational or gradual autonomy, the perspectives of those, whose means or options to participate are limited or who need support to be able to voice their positions, have to be focused and fortified. This involves patients or relatives, as they are lacking medical expertise and can additionally be part of specifically vulnerable groups, and also nurses and other medical staff, who are often suffering from a lack of representation in decision-making processes.
We will critically discuss the limitations of this approach. On the governmental and institutional level it is necessary to highlight the responsibilities for establishing conditions where the right to participation is made possible for everybody equally. In the individual context, the duty to support patients in their right to participation could become a burden, particularly when the institutional conditions are creating obstacles to do so. For patients or relatives, the right to participation might, in some settings, generate too much pressure. The focus on empowerment (of patients and of health care professionals) should primarily be an institutional task. The individual awareness, however, should also be an important target.

What's the big difference? The medicalization of assisted suicide and euthanasia vs. the medicalization of the death penalty
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Some countries oppose the medicalization of the death penalty yet have legalized physician involvement in AS/E (e.g., The Netherlands). Other jurisdictions require the former but prohibit the latter (e.g., several US states). This inconsistency is surprising since in both instances, the physician's intent is to end life and physician involvement is deemed necessary to assure a humane death. In this presentation, we review these seemingly paradoxical inconsistencies and examine whether they can be justified. One difference between both scenarios is that a death row prisoner is not a patient. But what is the ethical relevance of that fact, particularly since at least one country (The Netherlands) is moving towards AS/E for non-patients who consider their life to have become meaningless? Another is that death penalty convicts do not ask to be executed when patients seeking AS/E do seek death. However, even if death penalty convicts were to choose lethal injection from various modes of execution, that does not usually convince opponents of medicalized executions. Opponents of medicalized executions also cite reports that some prisoners have suffered greatly in spite of the involvement of health professionals. But similar claims have been advanced by opponents of medicalized PAS/E, pointing out for example that we lack reliable evidence about the manner in which patients die from PAS in Oregon. A review of the different assessments of medicalized executions and medicalized AS/E may help us to more precisely define the scope of practice of physicians and other health care professions vis-à-vis interventions intended to bring about death.

Ethical Climate for Healthcare Professionals: A Systematic Review
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In rapid aging countries, the older are people taken care at home, the more ethically tricky situations for healthcare professionals, ranging from withdrawing treatment of untreatable diseases to end-of-life care. Continuous care in community comprehensive support system through hospitals to home is not as simple as supposed. Only a few cases that were fought with ethical problems come to the front as opposed to many cases occurring in reality. There would be no ethical problems, if the professionals had enough moral senses and made morally right decisions. Then assessment of the moral climate becomes important. This study begins with definition of the ethical climate in clinical settings to support healthcare professionals in terms of their functions and goals. Although several definitions of the ethical climate have been proposed in previous studies, they are not reviewed and assessed yet for proper evaluation of the ethical climate. Peer-reviewed academic articles written in English were searched using specific Mesh terms and manual keywords in CINAHL, PubMed, Web of Science and Cochran's Library databases. In total of 546 articles worldwide described ethical climate approaches that include clinical ethics environment, ethical culture, and ethical environment. Most studies are established among nurses focusing on their relationships between peers, doctors and other healthcare workers. But even with well-developed communications, a lack of moral understanding may result in bad ethical climate. Also interrelationship among coworkers and physicians is not studied well as most of the researches are based on only nurses. The moral sense and responsibility for healthcare professionals needs to be considered in both individuals and peers for assessing in ethical climate settings.

Barriers to family involvement in mental health care during severe mental illness.

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Introduction: The Norwegian guidelines on treatment of people with psychosis disorders recommends family involvement, e.g. family psychoeducation. Research has shown that family interventions have the potential to increase satisfaction with care, health and well-being for service users and their families and improve the effectiveness of mental health care services and treatment. Despite of this, research shows that involvement of next to kin is lacking in mental health care. This work, which is part of a cluster randomised study on implementation of guidelines on family involvement during severe mental illness, aims to explore barriers for family involvement in mental health care, and how to overcome the barriers identified. Besides scientific evidence of positive effects, there is also a moral imperative to involve those providing unpaid care and support in collaboration with professional care.
Method: This mixed-method study has been conducted in 15 psychiatric outpatient clinics in eastern part of Norway from 2017 and will last until 2021. Data has been collected from various sources before and during the intervention-period; via participants at kick-off seminars, the reference group, during the recruitment-process at the outpatient clinics, through panel groups with all stakeholders including patients, next to kins and health care professionals, via baseline fidelity measurements on the intervention units, as well as focus groups including members of local implementation teams at the intervention-units.
Results: Preliminary analyses indicate several important barriers to family involvement among the stakeholders, at both the clinical, organisational and policy level. Many of the barriers are related to health care professionals struggling with moral dilemmas and conflicting interests, e.g. how to interpret the duty of confidentiality, uncertainty related to documentation and lack of competence and capacity to offer family psychoeducation as part of the treatment. Leaders

and health care professionals at the outpatient clinics actively seek advice and implementation support to handle these barriers and dilemmas. This implementation study aims to help them to deal with and overcome these barriers through systematic triadic approaches in an implementation program.
Discussion: There are compelling reasons to intensify the implementation of family involvement in mental health care, in particular during severe mental illness as psychoses. The need for better knowledge on how to succeed in implementing good practices of involving the patients` network is urgent. Facilitators and concrete measures to overcome such barriers on structural and organisational level will be discussed in the conference.

Crispr, Harm, and The Non-Identity Problem
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It is uncontroversial to say that we care quite a lot about preventing harms to future people. We might believe we ought to protect future people by ensuring they will have clean air to breathe, to not be impacted by nuclear radiation, or not to be born with some serious but not life-limiting condition. These are, I take it, intuitive examples of the kind of interests based on not being harmed that future people are believed to have.
While these beliefs are plausible, there is an argument that challenges them. When you harm some person who currently exists there is someone in particular who has been harmed. This view is called the person-based approach to ethics. Furthermore, particular persons whose existence is entailed by seemingly harmful actions do not exist in an alternative world, some other person would have existed instead and so they, in particular, cannot be made worse off. If the common-sense view of harm holds, then this person is not made worse off, and thus not harmed by that action. In combining these beliefs, we face an implausible conclusion when considering seemingly harmful actions against future persons: that seemingly harmful actions which affect future persons cannot be harmful at all. This challenge is rooted in The Non-Identity Problem, first posed by Derek Parfit (1984).
In this paper, I critically evaluate a belief about harming future persons in an applied context: the belief that we ought not to proceed with gene editing with Crispr, a technology that allows for the editing of the human genome, if it could harm future people. I call this the harm-based belief against the testing of Crispr on human subjects. The harm belief aims to influence the permissibility of testing Crispr by claiming it is possible that Crispr could cause unintentional harm to all future persons and so testing on human subjects is not permissible. This paper evaluates whether the NIP poses a threat to this belief. I argue that it does challenge this belief. In light of this challenge, I will show that the harm-based belief only accounts for first generational harm, and not harm caused to subsequent generations. However, the harm-based belief purports that it is possible to harm all future generations, and so there is theoretical tension that needs to be resolved.
I propose a solution to this tension. First, I explain some important technical distinctions and then turn to the arguments. I will explain the harm-based belief and explicate the NIP to show why it poses a challenge to the harm-based belief against testing Crispr on human subjects. Thus, I argue that the NIP shows that the harm-belief does not do the work that it is intended to do. I propose a remedy by arguing for a re-evaluation of the PBA to the ethics of future people. If this is plausible then we can avoid the challenge and retain the harm-belief.

Pandora's Pregnancy: NIPT, CMA and Genome Sequencing – A New Era for Prenatal Genetic Testing

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By inspecting fetal DNA through the growing variety of modern prenatal genetic diagnostic (PND) technologies, we also unleash complexity and uncertainty. We delineate in this commentary a shift from the "traditional" technologies of karyotyping in PND to the current phase of advanced genetic technologies including non-invasive prenatal testing (NIPT), chromosomal microarray analysis (CMA) and exome sequencing with their higher detection rate and related abundance of uncertain data. We consider the implications of this new era of PND for users and health professionals by drawing on previous studies documenting how probability and uncertainty affect informed consent/choice, health risks communication, customer satisfaction and decision-making, and parent-child bonding. We argue that these changes move us beyond the idioms and realities of the tentative pregnancy and moral pioneering, to "non-deterministic" counseling and moral/translational gambling. We conclude by discussing what is needed to maintain public hope in the era of Pandora's pregnancy.

Harm, Responsibility, and Justice: How Well-Intended Political Considerations Overshadowed the Ethical Case against Animal Suffering

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Medical and other scientific experiments cause suffering and anxiety to nonhuman animals. Simple ethics of harm reduction, right protection, and care dictate that we should put a stop to this. According to prevalent jurisprudential theories on causation and responsibility, we could even make legal reforms to stop it. The specific harm done to a particular animal by a patient taking a medication or having a treatment whose development has involved harmful experiments is in most cases unclear. The influential “But for” rule (we are only responsible for consequences that would not have occurred but for our own contribution) could therefore be employed to exonerate the users of dubious products and services. Key legal cases like Summers v. Tice and Sindell v. Abbott Laboratories indicate, however, that courts can assign contributory blame to agents who are jointly responsible for harmful consequences. If two (or more) culprits cause injuries to a third party, we need not ascertain the exact source of injury to make a considered judgement.

Yet experimentation continues, and only a minority of people see it as a moral or legal problem. I argue that this is due to a paradigm shift from simple ethical considerations to a more relativistic model of political bargaining. As my presentation will show, theories of justice present, from their own viewpoints, good cases for safeguarding one group’s interests against others. Since the justifications have approximately similar weight, the question ceases to be one about whether or not someone has caused harm, and it turns, in Antony Honoré’s words, into a question of whether we are looking at “harm of a sort that the law seeks to avoid”. In the new situation, the jurisprudential “But for” rule with its reasonable exceptions is replaced by a Vicky Pollard (TV series Little Britain) type of “Yeah, but, no but…” babble. A well-intended move from individual-centered ethics to wider considerations of social justice have forsaken the well-being and integrity of other species in the name of economic concerns, philosophical nitpicking, and anthropocentric ideological sensitivities.

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Priority setting in primary health care – a qualitative study on allocation of nursing home placements

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Background: The core ethical principles in the Norwegian welfare state are the principles of justice and universalism; all citizens should have equal access to health care services, including nursing homes, independent of where they live, socioeconomic status or age. Patients who apply for a permanent place in a nursing home are among society's most vulnerable. Hence, it is of great importance that the process of nursing home placement is fair.
Objective of the research: The aim of this study was to explore which criteria and values allocation of nursing home placements is built on, and whether the process is fair.
Methods: The study has a qualitative design. Data were collected through individual interviews and participant observation. Five executive officers in different municipalities who have the formal responsibility for the placements, and four GPs and seven nurses on short-term wards in nursing homes were interviewed. In addition, one of the researchers observed meetings where allocation of municipal health care services was discussed.
Results: Health care personnel in primary health care mainly agree on which criteria are the most important to safeguard the principle of justice. However, some unintended and less highlighted factors could jeopardize the ideal of fair and just allocation. Some of these were organizational variations, variations in the municipalities' economy, variations in individual judgments and resourceful and strong-willed relatives.
Conclusion: Our study indicates that some of the weakest and most vulnerable patients in the Norwegian society are not treated equally and fairly. In order to safeguard the principle of justice, specific national criteria should be used in allocation of nursing home placements. However, if unintended factors actually override the criteria, national criteria is not enough. We suggest that in addition to guiding criteria, we should be aware of the unintended factors, and focus on how to control them in a better way.

***mHealth*, self-management and empowerment: digital health technologies from a public health perspective**

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Mobile health (mHealth) technologies are a rapidly developing field. The opportunities brought forward by these technologies have been lauded by some, who emphasize their potential for

positively transforming health care provision and perceive them as novel tools for ordinary people to gain control over their health. This paper investigates whether and under which circumstances these technologies can generate good public health outcomes and empower individuals and communities in a healthcare context.
The incorporation of mHealth technologies into the daily lives of 'health consumers' is increasingly being promoted as an avenue to strengthening patient autonomy and improving population health outcomes. Advocates for the routine use of mHealth argue that these technologies facilitate better-informed health choices and provide access to healthcare to a wider cohort of individuals at lower costs. In their view, health professionals and caregivers are able to diagnose and monitor individuals without face-to-face visits, while individuals can self-manage, which enhances preventative to post-operative care.
However, the emphasis on self-management implicit in mHealth raises ethical concerns. The expectations that individuals are able to and ought to engage in self-monitoring and self-assessment of health is particularly problematic. Some have argued that the individualisation of health outcomes is troubling as it fails to account for broader socio-economic and political factors, which shape individual, public and global health. Hence, the shift towards self-responsibility for health might increase health inequities, undermine social justice in health and potentially introduce a new digital healthcare divide. Moreover, mHealth technologies raise further concerns regarding data security and algorithmic bias, which can exacerbate users' vulnerability in a healthcare context.
Based on an interrogation of the possibilities, benefits, challenges and risks associated with mHealth, I argue that these technologies can facilitate good public health outcomes and empower users when they are grounded in principles and values including justice, equality, diversity and solidarity.

DTC GT in a Small and Homogenous Population: The Future of Health Care or a Pandora Box of Insurmountable Societal Challenges?

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During breaks in the televised broadcasting of the Eurovision Song Contest, the Icelandic public was presented with advertisements from the Israel-based company MyHeritage which operates online. For many people, this was the first time they have been made aware of a company of this sort. Although people are very technology savvy and extremely willing to participate in various forms of scientific research, the marketing of direct-to-consumer genetic testing (DCT-GT) has not made much progress in Iceland until now. One can conjecture many reasons for this. There is, for example, quite significant and readily available genealogical information online for the Icelandic public. Another reason could be the strong presence of deCODE Genetics in Iceland in all things related to human DNA. Despite small steps roughly a decade ago into consumer genetics, the company has until now firmly focused on gathering anonymized genotypic and medical data from volunteer participants for research purposes.
DCT-GT could, however, easily become a very potent tool within a small and homogeneous population if any substance is in the promises of the most prominent companies on the market. It fits, for example, perfectly ideas how personalization of medicine can help already strained solidarity-based health-care systems. Furthermore, it seems to blend into an existing discourse on individual responsibility and empowerment in health-related matters. Lastly, one can easily imagine that once better known a part of DCT services promising information on genetic ancestry far back in time could tickle the curiosity of a geographically isolated nation with tales of travelling individuals disproportionally influencing the local gene pool. In this talk, I will

ask whether a small and homogenous population is perhaps indeed particularly vulnerable and not sufficiently prepared for the challenges of privacy and scientific validity commercialized genetic testing brings with it. Are the perceived and promised advantages worth the risk if the correct precautionary steps are not taken? The identification and development of these steps will be the next big project in bioethics in Iceland.

Health technology and algorithmic fairness

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Many different kinds of new medical technology make use of predictive analytics in order to promote better health outcomes. Predictive analytics applies what I will call a predictive algorithm that is informed by big data on data about an individual to make predictions about the individual. When used in the healthcare sector, predictive analytics can help patients monitor their health-conditions and enable better self-medication, and it can improve the accuracy of medical diagnoses. However, it has recently been proven that unless the algorithm used to make predictions provides perfectly accurate predictions or the sought-after property (e.g. a health condition) is evenly distributed across groups, the predictive algorithm will violate at least one of three fairness axioms. Either (i) the algorithm correctly identifies the relevant property (e.g. a health condition) more often in one subgroup (e.g. men) than another (e.g. women); (ii) the algorithm produces more positive false findings of the property for one subgroup; or (iii) the algorithm produces more negative false findings for one subgroup. Otherwise put, predictive algorithms are in many contexts inherently discriminatory and exhibit the characteristics of wrongful discrimination that is non-intentional, but which results in different impacts on individuals based on what subgroup they belong to. This paper outlines and explores different responses to this problem: should we abandon predictive algorithms, compromise on equality in correct predictions across subgroups, or accept inequality between subgroups with respect to false findings? With reference to how the alternative costs of abandoning predictive algorithms are high and the results risk being even worse in terms of wrongful discrimination, that option is discarded as undesirable. The paper instead presents three ethical principles that should be universally applied to promote algorithmic fairness in relation to new health technology: (1) *Transparency*: those who promote the use of predictive algorithms should be aware of the unintended differences in impact and also be transparent to the affected community about these unintended differences; (2) *Dominance:* an algorithm that is better with respect to one of the three dimensions of fairness and worse with respect to none is better overall; and (3) *Priority to the worse off*: an algorithm that is relatively better for members of a worse-off subgroup is preferable to an algorithm that is relatively better for members of a better-off subgroup. Yet, the paper concludes that all-things-considered judgments about the fairness of predictive algorithms are context-dependent. They depend on the what is predicted, and what the negative consequences of false findings are.

Epistemic injustice in clinical ethics consultation

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Epistemic injustice occurs when a person is treated in an unjust way in relation to their role as a reliable provider of testimony, or in relation to their role as a legitimate member of a particular epistemic community.

This paper will analyse whether some clinical ethics consultation practices involve epistemic injustice towards patients, relatives and some groups of health care professionals. The focus of the analysis will be patients, but it will briefly be shown how this analysis can be extended to other groups.
The point of departure of the analysis will be the general acknowledgement that the provision of good quality clinical ethics advice requires a good understanding of the clinical situation and the ethical issues it actualises. Clinical ethics consultation therefore necessarily involves epistemic work within a particular epistemic community. This can be a circumscribed epistemic community e.g. a clinical ethics committee considering the case, or a more fluid epistemic community e.g. a clinical ethics consultant and the relevant stakeholders.
It will be shown that this epistemic work often requires information about the patient that is not purely medical or clinical, e.g. information about the patient's experiences, values, preferences etc. In some clinical ethics consultation processes this information is not obtained directly from patients or patients are not included in the epistemic community. If the process requires the patient's testimony to be mediated by a professional (or others), or in other ways deliberately excludes the patient from the epistemic community, there is a *prima facie* case of epistemic injustice (i.e. of treating patients unjustly in their capacity as competent epistemic agents). A number of possible justifications for handling patient testimony in this way will be analysed and it will be shown that none of them provides a sound justification for implementing clinical ethics processes that by design exclude patients from full epistemic participation.

The dark side of care - Inadequate care, abuse and neglect in Norwegian mental health care

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Introduction: Parallel to increased attention on issues related to users -rights, -experiences and -participation in mental health care (MHC) services, users experience of inadequate care, abuse and neglect have got heightened attention. The behaviours described stretches from being treated with disrespect, thru verbal scolding to physical violence. The purpose of this study was to investigate if and to which extend users and staff have experienced/performed, witnessed or heard about inadequate care, abuse and neglect toward users by staff during MHC. Since these issues are scarcely investigated, the study had an explorative design.
Method: Data was gathered thru an anonym web-based questionnaire to users and staff. Staff was recruited thru the professional's organizations and users was recruited thru Norwegian user organizations. The study was part of a comprehensive multi-centre study investigating different ethical aspect in relation to care and use of coercion in mental health care services. Altogether, 1160 staff and 320 users answered the questionnaire about their experiences with different kind of inadequate care, abuse & neglect toward users under mental health care.
Results: Users had experienced a wide variety of form of inadequate care, abuse and neglect during mental health care: As much as 67 percent had experienced disrespect; 63 percent had experienced condescending behaviour and 59 percent had experiences of rejection. Staff verified the high amount of inadequate care, abuse and neglect during care: Altogether 21 percent og the staff said they had treated patients with disrespect; 16 percent said they had performed condescending behaviour. And 46 percent said they had rejected patients.
Discussion: This study shows that some users experience inadequate care, abuse and disrespect during care. Staff verify the findings by also answering that they have performed themselves, observed and witnessed inadequate care, abuse and disrespect of users during mental health care. The paper discusses different alternatives of explanations and risk factors for inadequate

care, abuse and neglect; like staff burn out, high work load, staff insensitivity, lack of empathy and lack of good role models/leadership.
Conclusion: A disturbing high number of users and staff reports about users being treated with inadequate care, abuse and neglect during mental health care. Users in mental health institution care are vulnerable and at risk of inadequate care, abuse and neglect because of the imbalance in power between staff and patients in the institutional setting. It is therefore of considerable scientific value and important for this group of vulnerable users that this issue is to be further examined. User's experiences of inadequate care, abuse and neglect should be taken seriously, and effort should be made to prevent this practice.
Founding: The project has received funding from the Norwegian Health Directorate and Extrastiftelsen (NGO founding).

Whose Vulnerability? Rethinking the Violence Against Physicians
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At the end of 2018, a psychiatrist at a general hospital in Korea was brutally killed by a patient. In the recent years, violence against physicians has become a social problem. It seems that such violence most often occurs in hospital emergency room or in psychiatrist's clinic. Violence against physicians is a serious offense in that it not only injures the physician him/herself but also do harm to the patients he/she takes care of. Moreover, such act of violence should be considered as a subject of philosophical reflection that challenges the traditional model of patient-physician relationship.
Traditionally, philosophical and ethical discussions over patient-physician relationship were mainly focused on the confrontation and compromise between patient's autonomy and physician's paternalistic intervention. In such cases, it was usual that the principle of respecting patient's autonomy be considered primarily. There was also an implicit assumption that patient needs to be protected by the physician as a vulnerable being. In this regard, violence against physicians can be interpreted as an evidence that reveals how the authority of physicians, that has been traditionally appreciated in community, is being destroyed. The power gap between patient and physician in clinic is currently becoming dramatically reversed by the deviant behavior of violence. Nevertheless, explaining violence against physicians merely as deviant behavior of an individual patient conceal the institutional and structural contradictions that exist beneath the violence.
Such phenomenon may be understood as what Habermas had termed as the *Kolonialisierung der Lebenswelt(*colonization of the lifeworld) by the system that pursues efficiency under capitalist regime, and the medical field is no exception. The vocational ethos of physicians under the traditional patient-physician relationship that is based on mutual understanding and trust is being disrupted by the logic of system. Moreover, with the emergence of neoliberalism and rapid capitalization of medical care, the very condition of social discrimination and inequality produces diverse vulnerable beings in the medical field.
After the IMF foreign exchange crisis in 1997, Korean society consistently underwent polarization of wealth and deterioration of working conditions, which exacerbated discrimination and hate against minorities and immigrants. This serves as condition that makes individuals vulnerable to disease. In addition, the deterioration of the quality of medical care caused by commercialization and the withdrawal of medical communality resulted not only the suffering of patients but also the condition of overwork and burnout as well as the violence to (or, between) physicians. In this aspect, physicians too, cannot overcome vulnerability.

Therefore, it is necessary to overcome the stereotypical perspective over the power gap between physician and patient and reexamine patient-physician relationship through the concept of 'vulnerability' in the broader context of medical institution, society, nation state and transnational public sphere.

Are we asking the right questions? Ethical issues of digitalization and new medical technology in care of the elderly

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Digitalization and the use of new technology in the care of elderly and demented persons has led to new ethical debates. Academic ethical reflection, deliberation among care givers as well as a public debate have been established in recent time, all of them trying to define what is at the center of good care and how technology can contribute to this.
The paper takes it starting point at the perspective of students of care of the elderly. In five workshops at schools for future nurses' students discussed their ethical perspective on three examples of medical technology in care: social bots, geo tracking using GPS technology and monitoring of health-related data. Students produced media contributions (audio, video and posters, 21 contributions in total) in order to engage in and inform the public debate about these ethical issues. The workshops took place in 2018 in schools in the south of Germany and were part of the project "Modern medical technology in nursing homes?" funded by the German Ministry for Education and Research. The normative aspects of the media products were analyzed using a qualitative-hermeneutic research approach. Students of nursing place the well-being of their clients at the center of their reflection. Their evaluation of new technology askes how the everyday practice of nursing might be changed by implementing new technology and how this might affect their clients. Their discussion is based on their perspective on and daily experience of their profession and thus refers also problematic aspects such as a growing lack of nurses and job vacancies, experiences of work overload and time pressure, low esteem for nursing profession in society, power play between generations of nurses and experiences of violence by and against nurses. In their discussions and media products they present an image of nursing that is far from ideal or text book like. Within this description of nursing they ask how technology might improve the situation and how elderly and demented persons can benefit directly or indirectly by the use of new technology.
The ethical aspects found in the media products is compared to the results of a review on the ethical issues in the academic debate. Here the starting point is the (alleged) functionality of a technology and the comparison to other offers e.g. by humans within nursing practice. In this debate we also find the idea of beneficence at the center but within a different conceptualization of situations of nursing.
Based on the results of the comparison between the two strands within the debate the paper askes what normative consequences can be drawn from the differences and what the implications for participatory processes in nursing and technology development are.

Availability of post-trial access in clinical trials: a review of clinical trial protocols submitted to the Research Ethics Board of the University of the Philippines Manila

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Ethics guidelines such as the Declaration of Helsinki and the CIOMS International Ethical Guidelines for Health-related Research Involving Humans require the sponsors, in cooperation with relevant stakeholders, to provide post-trial access (PTA) to intervention and knowledge, especially in clinical trials held in resource-poor regions. To date, we have very limited knowledge in terms of whether PTA is provided at all, and in what form. To partially address this current limitation, this study wishes to explore whether, for which type of drugs, and in what form PTA is provided in the Philippines.
We looked at all the clinical trial protocols submitted to the University of the Philippines Manila from 2012 to 2017. A total of 193 clinical trial protocols were included in the study. To identify whether, for which drug type, and in what form PTA is provided, we gathered the following information: begin and end date of the trial, name of study drug, tested indication of the study drug, region the sponsor is from, type/category of the study drug, type of funding agency, provisions for PTA (yes or no), and the explanation for the provisions. PTA provisions were further described to determine what form PTA was provided and which types of drug were given for PTA.
Of the 193 protocols, 51.81% indicated PTA, the most common form being the provision/sharing of information (40 protocols). None of the protocols provided PTA in the form of access to intervention after the trials, with the possible exemption of 10 protocols that declared future evaluation of the sponsor for PTA depending on patient need, and another seven that might offer the option to transfer to an open-label extension study after the trial. A lot of work needs to be done if PTA, as stipulated in ethics guidelines, is to be fully reflected in reality.

Ethical Challenges in Genomic Approaches to Infectious Disease: The Case of Phylogenetic Tuberculosis Sequencing
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Advances in DNA sequencing have enabled us to differentiate between strains of pathogens in detailed ways, bringing "precision medicine" to the diagnosis, treatment, and prevention of infectious disease. In fact, in the case of tuberculosis, the marriage of genomics and the germ theory now allows us to trace the provenance of individual clinical cases to very specific sites of endemic TB, including particular refugee camps, prisons, and conflict zones around the world. This is a boon for epidemiologists tracking the global spread of the disease, but also raises questions of privacy and the risks of stigmatization and unfair social discrimination for patients, especially in the context of immigration, public health, and national security policies that involve health screening. Implementing such a program will mean bringing to bear considerations from both traditional public health ethics and the emerging ethics of genomic information storage and disclosure. This presentation reports on the work of a University of Antwerp-based European group attempting to address these issues, as an example of the ways that genomics can challenge society beyond the clinical setting.

Posthumous paternity
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The accomplishments of modern medicine enable both the posthumous harvesting of sperm, and the birth of a child with the foreknowledge that he or she will be a paternal orphan. Posthumous paternity (posthumous parenthood, "parenthood from the grave") raises many

questions in the domain of psychology: paternity, in particular (is this the deceased's "biological will"), and parenthood, in general. It also raises questions regarding multi-generational relationships, ethics, law, and financial questions.
Questions regarding the deceased: Does posthumous harvesting of sperm negatively affect the deceased's dignity? In the absence of a will—how can it be determined if posthumous paternity was what the deceased wanted? If the child was born to a single-parent mother who procured the sperm from the deceased's parents, and they chose the woman who would become the mother of their grandchild, rather than the deceased parent who did not know her. It is possible that the mother's motive for giving birth to the child was her desire to receive the deceased's inheritance.
The disadvantages of giving birth to an orphaned child through posthumous paternity are many: disproportionate pressure put on the widow to have the child; the lack of a father figure during the child's developmental years; over-involvement of bereaved grandparents to the point of conflicts between them and the mother; and the stipulation of the mother's acceptance of their authority as a condition of their assistance in rearing the child. If the deceased parent died of a disease that may be genetically passed on to the child, the latter grows up with a problematic genetic profile.
If the grandparents' function as parents, the child is raised as a memorial to the parent from whose sperm they were conceived, they are expected to prove themselves in areas significant to the grandparents, they are compared with the deceased father and raised by older, bereaved parents.
However, there are also advantages to a posthumous child: the birth of the child was desired and intentional; the mother, though she may be a single mother, receives a substantial amount of support from the parents of the deceased from whose sperm the child was conceived. Unlike a child conceived by means of sperm purchased in a sperm bank, the posthumous child knows their father's identity, and is often socially commended if their father was killed in a war or was a highly accomplished individual.
Unlike a child adopted in the framework of "closed adoption," who only at age eighteen is given the opportunity to meet their biological mother (in most cases, not the father)—on condition that she agrees to reveal her identity and meet—and unlike a child born from the sperm of an anonymous donor, a posthumous child knows the parent's identity. However, while an adopted child usually has two parents, a posthumous child is a paternal orphan.
Should society encourage the birth of posthumous children to single-parent mothers and to bereaved grandparents? Is the birth of their son's posthumous child the right way to deal with grief?
The medical achievements regarding posthumous fertilization are far less advanced than the ethical and legal answers to these issues.

Who Is Responsible for the Care Crisis in Modern Medicine?

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According to the care crisis in modern medicine, the existential needs of patients are not satisfied. Marcum (2012) believes that if physicians become virtuous and implement their medical practices in agreement with prudent love, this crisis will be solved. He maintains that this idea has a profound implication for the premedical and medical education of medicines. He suggests that the curriculum of medical students must include some general humanities, specific medical humanities, and practical clinical courses. According to him, by so doing, physicians will become more virtuous and care crisis will be eased.

Although this solution is partly acceptable, it does not completely figure out the problem. In this paper, it is argued that the care crisis is to some extent due to the undeniable role of technologies in modern medicine, so even if all physicians were virtuous, the problem would to some extent continue to exist. Indeed, the advent of Imaging technologies affects physicians' understanding of disease and diagnosis. Disease is now a materialistic thing detectable by technologies, and patients' narratives are not a necessary part of physicians' diagnosis. Physicians do not need to have a conversation with their patients since every disease can be detected by technologies. Therefore, technologies make a huge distance between physicians and patients, thereby exacerbating the care crisis which is the consequence of the poor relationship of physicians in association with their patients.
At the end of the paper, a comprehensive ethical approach including the evaluation of all contributing parts is proposed. According to this approach, health care system should be seen as a network whose components are physicians, patients, nurses, procedures, technologies and so on. The factors having an influence on the relationship between physician and patient should be recognized and evaluated. Especially, the influence of each technology and its mediation on the relationship between physicians and patients should be evaluated, and accordingly, new prescriptions about the system and its components and their relationships should be written. Technologies ought to be lain in a suitable relationship with other components in order not to harm the care value. The new network including various mentioned factors (especially technologies) should take into consideration the role of patients' narrations and the importance of the relatedness between physicians and patients.

The Use of Homeless Populations in Phase 1 Clinical Trial: Is It Ethical?
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Pharmaceutical companies are under constant pressure to enroll participants into clinical trials as they seek approval for new drugs. This is especially difficult in the studies of psychotropic drugs and their effects on individuals with mental health disorders. In the last decade, experiments that were organized in academic settings were moved to private sector companies. With the absence of strong regulations in Phase 1 clinical trials, there has been an increase in the use of the homeless population for the experimentation of antidepressants and antipsychotic drugs. This phenomenon has risen from the difficulty in finding participants with mental disorders able to join clinical trials and it has found that the homeless provide an ample and often willing subject pool (Elliott, 2014). Homeless can be easily recruited into clinical trials with the promise of compensation in the forms of money, lodging and food. Harm that could ensue from clinical trials is almost never discussed. This paper will explore the use of the homeless population as a viable alternative to participants in clinical trials, whether their agreement to enroll truly reflects informed consent, and whether large monetary compensation impedes the validity of the clinical trial findings. In addition, will the homeless benefit from the drug when it is available? Will they benefit from the study drug even before it is approved, as well as the supportive care typically available during trials?

Medicine at the Edge of Bioethics
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The theme of this year's conference is provocative: How should we understand and evaluate activities, practices, and industries "at the edge of medicine"? Do they belong to the domain of medicine and health care, and therefore to bioethics, or should they be guided by considerations external to medicine? These essential questions are subject to both inadvertent and intentional misuse. I examine the pitfalls in the premise and propose that bioethics take a different direction.

The question whether new scientific activities belong to the domain of medicine is rarely answered in the negative. Ensuring that developments at the edge of medicine and science fall within scientific medicine's grasp is a primary goal of academic bioethics because it ensures employment for bioethics scholars. The human genome, the human microbiome, epigenetics, regenerative medicine, genome editing, chimeras, de-extinction, gene drives, artificial intelligence – all these novel technologies, and more, have in recent years become funding sources and subjects of publications by thoughtful and ambitious university professors from disciplines represented in bioethics.

These developments both expand the scope and authority of bioethics and create more silos of narrowly focused expertise. Thus they increase the power and voice of the field while at the same time making interdisciplinarity and communication across silos much more difficult. At the same time, the market value of medical and scientific data is increasing. Medical centers are becoming learning healthcare systems so that they can benefit in a variety of ways from blending research and treatment and expanding their datagathering, in order to acquire more research funding and market what is learned. The professionalization and certification of clinical ethics consultation in the US is following a similar path.

Most troubling about the expansion of medicine, and the consequently expanding authority of bioethics, is the medicalization that follows. Most troubling about the expansion of medicalization is that it increases public pressure to seek technological solutions to social problems. This trend gives undeserved credence to the overbroad and justly criticized WHO definition of health. A definition of health that includes everything means that everything else matters only insofar as it is instrumental to health. If everything is instrumental to health, then medical treatments are the answer to everything, and biotechnology is the solution to every social ill.

The alternatives to these technological solutions are obvious, but difficult to enact. They are not new and attractive to funders but require significant long-term commitments to broad communication and collaboration. Bioethics scholars should work to de-professionalize what bioethics offers and find common ground with other ways of addressing the problems of people and the planet, which are intertwined and require a combination of technological, social, and very basic solutions. Perhaps most important, it is not even possible to address these problems without reaching some bigger conceptual questions. How should we regard public health, rescue medicine, the place of science in society, and the balance of shared responsibility for health and wellbeing, in individual societies and worldwide?

Surrogacy as a practice of autonomy – an attempt to formulate a practical concept

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Surrogacy still remains illegal or unregulated in many countries in the world. Undoubtedly, it is one of the most controversial issues in contemporary ethical and legal debates on human reproduction. These debates include various arguments. In my presentation I will focus on a group of arguments referring to the principle of respect for a surrogate's autonomy and the limits of a woman's right to freely use her own body.

I will present a range of practices that nowadays are included under "surrogacy". Although they are similar, there are important differences between them. Some differences result from the difference of context e.g. surrogate's economic situation, others from reasons behind the woman's decision to enter surrogacy arrangement or her educational background . In all debates about surrogacy a key issue is, however, that of the surrogate's autonomy, as it relates to various contexts, reasons and backgrounds.
In this talk I will examine the issue of the surrogate's autonomy and various ways in which it can be respected or violated. In particular, I will focus on the practical issue of assessment of the surrogate's ability to give informed consent and to be autonomous in her decisions regarding entering a surrogacy arrangement.

Best interests at the edge of medicine: The case of child protection interventions
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The principle of the child's best interests has undoubtedly become the most important guiding principle in the protection of children's rights. The United Nations Convention on the Rights of the Child, ratified by a vast majority of countries in the world, provides in Article 3: *"In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."*
Safeguarding and promoting children's wellbeing is not only morally required, as well as demanded by law, but also plays a key role in the proper functioning of the modern democratic state, which has a critical and legitimate interest in children as future citizens. Thus, child protection has been formalised into a system with wide interventionist state powers, allowing interference with otherwise highly protected citizens' rights and liberties, such as the right to family and private life, to protect the child from harm. Child protection is thus another positive obligation of the State towards children, in addition to the provision of healthcare and education. It is as important for the welfare of the child, and oftentimes as controversial. Cases comparable to those of Charlie Gard and Alfie Evans also exist in child protection, with public debates questioning the justifications provided and challenging the decisions made "in the best interests" of a child.
A fundamental challenge of "best interests" as a guiding principle in child welfare considerations lies in its practical applicability. As a conceptual principle, it is effective in that it serves as a reminder for keeping the child at the centre of our considerations at all times, that other parties' interests sometimes have to give way to those of that are more vulnerable. In practical terms, the translation from principle to rule poses significant difficulties, as this requires the application of a general principle to an individual child. A child-centric approach necessitates the assessment of the particular child in any given case, whether in healthcare or in child protection, but can we confidently argue that this effectively happens in practice? What are the learnings from the two fields with regard to defining "the child" in the application of the best interests principle? Can medicine and child protection learn from each other by giving substance to the principle?
Following a child-centric approach, this presentation focuses on the child as an individual – with individual rights and welfare needs. Arguing that much can be learnt from cross-disciplinary knowledge sharing, I suggest a common approach to best interests assessments concerning a particular child. In addressing some of the most serious decisions affecting the life of a child, which are often controversial in the public's opinion, we can improve our

understanding of the ethical challenges associated with such decisions and hopefully enhance public decision-making with regard to children.

Behaviour-based insurance models: a just allocation of resources?

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Sharing personal fitness and nutrition data with health insurance (HI) providers to receive a bonus is already being widely practiced in the US, and also German private as well as statutory HIs begin to offer insurance models which reward healthy lifestyle. A health-performance related insurance approach is based on various technologies such as tracking apps or artificial intelligence, which are not (yet) classified as E-medical products since these technologies are not primarily applied for medical purposes. Yet, applied technologies to track steps with a smartwatch or analyse sleep patterns become more and more used in daily life worldwide.
However, combining technology based (online-)monitoring and reward systems rises ethical questions such as whether a system, creating allocation of resources, thereby implying also the exclusion of resources ('rewards'), is just. While physically fit customers are rewarded, physically impaired might not be able to access all available options, such as step tracking (e.g. in the case of wheelchair users). Certain conditions would exclude users from parts of the programme and consequently penalise them for having a disability or chronic disease. Further, certain rewards can be collected only if the insured person subscribes to a gym, buys a smartwatch or purchases similar products. The cost for these gadgets and memberships are neither covered by the HI nor by the disbursement of rewards thus excluding low-income insured customers. In addition, health tracking requires use of electronic devices, for which customers have to have adequate digital literacy. This cannot be generally presumed for all customers thus further excluding certain groups. In addition to questions concerning unequal access, an allocation of rewards within the programme creates further dilemmas. On one hand, such reward systems often face the problem of the so-called Matthew-Effect, i.e. only the healthy participate and get the bonus. On the other hand, certain reward systems seem to advantage especially those who have lived an unhealthy lifestyle and start trying to change it by joining e.g. a smoking cessation or weight loss programme, instead of those who have always taken care of their health. In sum, the allocation of resources in a behaviour-based remuneration system is prone to discriminate against or disadvantage several groups.
Furthermore, and addressing the question of exclusion socio-ethically, this development challenges the principle of solidarity underlying at least German statutory HIs. Ideally, they protect their customers against risks and special vulnerabilities that come with illnesses or injuries – without monitoring. Basing the whole insurance on a behaviour-dependent model would lead to stratification, comparable to private HI, and reinforce the development of low premiums for healthy policyholders, rapidly increasing contributions for assured with chronic diseases or repeated illnesses and no insurance for already ill aspirants. Therefore, the already existent behaviour-dependent HI models not only raise questions of just resource allocation, but also tackle the roots of the (German) social insurance system.

Incorporation of the principle of the child's best interest in end of life-decisions for infants

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Medical success has made it possible to save very premature children and children born with severe conditions. In many cases this results in providing meaningful lives for the children, and lifesaving treatment is in accordance with the principle of the best interest of the child. However, in some cases the lives for these children have limited quality even though the medical technology has saved them.
The legal and ethical situation is clarified for infants who cannot be saved, and for infants who can be saved to an acceptable quality of life. The situation in between, however, is not clarified: We do not have the legal and ethical answer regarding when it is right to treat and when it is right to let die for infants who can survive with massive treatment, but with severe consequences.
According to the Convention on the Rights of the Child (CRC of November 20, 1989) Article 3, the responsible doctor's decision shall be based on the best interest of the child as a fundamental consideration. In 2014 Norwegian legislators included Section §104, into the Norwegian Constitution (of May 17. 1814) which, as in the CRC, makes children's interests a fundamental consideration.
According to the Patients´ and Users´ Rights Act (of July 4. 1999 no. 63), the child's parents shall practice the child's autonomy, hereby consent to or deny treatment. Parents shall, according to the Children Act (of April 8. 1981 no. 7), practice the parental responsibility in accordance with the child's best interest. A child's best interest consideration raises several moral questions e.g. about what quality of life is, and whether it is morally and legally acceptable to have a family-based approach while considering the child's best interest. It is also an ethical question whether it is possible to say that death could be in the best interest of a child, since without existence there can be no interest at all (Inwald, 2008).
The Committee on the Rights of the Children has in General Comment no. 14, "The right of the child to have his or her best interest taken as a primary consideration", given some guidelines about the content of the principle of the child's best interest, but do not deal with medical decision-making specifically. The Norwegian Directorate of Health has made guidelines regarding end of life-decisions (IS/2091. 2013), but they do not elaborate the content of the child's best interest for infants. The guidelines focus e.g. on the right of the child to be heard, which is an essential part of the child's best interest, but infants who were born severely ill have limited ways to express themselves due to lack of language and experience as a healthy baby.
I will argue that we need to scrutinize the content of the child's best interest consideration in end of life decision-making for infants, to develop a useful tool to incorporate this important principle in the decision-making process.

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For the Sake of Convenience? Implantable Microchips and the Future of Work

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Human-implantable microchips are a rapidly emerging technology no longer confined to the world of garage biohackers and so-called transhumanists. Several companies in the UK and elsewhere are already producing and selling these devices at low prices to both consumers and industry (e.g. UK's Bioteq and Sweden's Biohax). Here, we will map the ethical implications of the potential 'backdooring' of this type of technology through the workforce; who may not have a true choice of whether or not to engage. In the US and Sweden, there are a number of instances in which companies are trialling these on their employees for purposes ranging from health-related monitoring to secure building entry, computer access, and even travel ticketing. In many jurisdictions it is not expressly illegal for such an intervention to be a condition of employment; and where such trials are supposedly voluntary, they are frequently incentivised and strongly advocated by the employers in question. Reports emerged in November 2018 that major UK legal and financial firms, some of which have hundreds of thousands of employees, are in discussions with companies such as Biohax about deploying implantable chip technology themselves on a grand scale.
This has generated concern amongst trade unions and business spokesbodies about the potential for these devices to infringe on privacy rights and to be used as surveillance tools, as well as other uses beyond the basis on which they are promoted to employees. The emergence and growth of chip implant technology is beginning more generally to inspire bio- and techno-ethical questions around bodily integrity and identity, autonomy, human enhancement and cyborgism; as well as issues raised by the collection of biomedical, personal, and potentially location data by chips currently being developed. Any such implantable device also raises legal and regulatory questions in the areas of data protection, human and privacy rights, employment law, and around the implantation procedure itself. It also remains unclear how far employees - and the public more generally - understand the potential ethical, legal, social and health implications of accepting implantation; or the fundamental ways in which it is likely to disrupt the traditional boundaries of work by being part of their 'non-work' life. This paper will explore the new ethico-legal space engendered by the commercialisation of non-medical implants and their deployment by employers and lay out the foundational concerns for policy decision making regarding their use.

Organoid biobanking for precision medicine: stakeholder perspectives
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Organoids are 3D cell structures grown from stem cells that function, on a basic level, like actual organs. This technology promises a variety of scientific and clinical applications, such as disease modelling, precision medicine, and clinical transplantation. Already, intestinal organoids derived from patients with Cystic Fibrosis are being stored and used to find personalized treatment, both by testing the efficacy of existing drugs on organoids stored in a biobank as well as testing new pharmaceutical compounds. Storage and use of organoids for precision medicine also revives old and raises new ethical challenges, such as around the moral status of organoids, privacy, ownership, commercialization, the convergence of public and private domains, and the blurring boundary between research and care. In light of these challenges, adequate governance of stakeholder interests is crucial. In order to explore these interests, we conducted a qualitative study to map the needs, preferences and opinions around the ethics and governance of organoid biobanking for precision medicine for CF. Around 45 semi-structured interviews were held with experts, from both academic and commercial backgrounds, and CF-patients. In this presentation, I discuss the results of this empirical study,

categorized in four main themes: (1) the central position of the consent procedure, (2) challenges and opportunities regarding the blurring boundary between research and care, (3) views on how to balance the interests of stakeholders and (4) the importance of trust. These findings can be used to guide the further development of responsibly storing and using organoids via biobanks for medical research.

Regulations on Direct-to-Consumer Genetic Testing in Taiwan and China: Current Status and Problems

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In the past decade, more and more private companies have offered direct-to-consumer genetic tests (DTCGTs) in Taiwan and China. Many of these DTCGTs have provided no or only minor clinical utility and been conducted without genetic counseling. Some misleading terms such as "genes for losing weight," "intelligence genes," or "personality genes" have been often seen in advertising on Internet. A few companies in China even publicly announced their business plans to partner with insurance groups to use DTCGTs in insurance underwriting. This study aims to review the current regulations on DTCGTs in Taiwan and China and identify their deficiencies.

Potentiality, Futures of Value, and Abortion

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Don Marquis has famously argued that most abortions are morally wrong, because they deprive the embryo of a certain potentiality, i.e., a future of value like ours. However, his argument assumes the traditional view that potentiality is an intrinsic property of the embryo and that this potentiality is determined by what the average or most members of the kind are likely to realize in the natural or normal course of events and if nothing intervenes to prevent the potentiality from being realized. I argue that these assumptions are mistaken and that a more ethically relevant concept of potentiality will take into consideration how factors extrinsic to the embryo may affect its potentiality. Because any appeal to potentiality as having some ethical relevance involves assumptions about the actual possibility of the potential being realized, if there are physical conditions or respect for ethical rules that impede the realization of the potential, whatever ethical significance the potentiality has cannot be evaluated independently of consideration of whether those impediments can or should be removed. Marquis's argument fails because he fails to provide an ethical justification for the relevance of the concept of potentiality assumed in his argument. I argue that there are good ethical reasons for thinking that the intrinsic factors affecting potentiality are not the only relevant factors to consider in drawing a conclusion about the morality of abortion. The relevant sense of potentiality in the practical, ethical context is not "what would happen in the natural or normal course of events to the average or most embryos, if nothing outside of human action intervenes to alter that course." Instead, the relevant sense of potentiality is "what would happen in the natural or normal course of events to particular embryos, if nothing outside of human action intervenes to alter that course or if no ethically justified action is taken to alter that course."

Evidence-based medicine – a critical history

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The term Evidence-based medicine (EBM) was introduced in the early 1990s and became soon very popular. Rather than being a new way of practising medicine, it could be characterized as a movement that introduced the tools of clinical epidemiology to practising physicians. From the early years on, EBM has also inspired its critics. The movement has listened to the critics and redefined EBM several times. However, the term EBM has also been widely misused as a marketing tool and as a buzzword. The early EBM was essentially anti-authoritarian but the latest definitions have highlighted the importance of expertise again. The EBM movement has done a good job but the term as such is used in so many meanings that it is questionable whether we need it any more.

Is a more paternalistic framework needed to respect and enhance participant's autonomy? The challenge of electronic informed consent

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Personalized medicine and participation in biobanks are often presented (not to say marketed) as the key to get the best health care, to get if not now, then in the (near) future the most from what medicine has to offer. Although we could ask and debate is this a valid claim, the focus of this talk is on a new challenge – the growing usage of electronic informed consent in human subject research. Although there is the widespread accepted principle that participation in human subject research should be voluntary, the electronic form as a new context brings (up) the question about the proper ways _ to respect it or even the question is the principle still valid or is outdated cannot be escaped.
Traditionally the questions to ask were how to make sure that the person understands the difference between research and therapy and that it is participation in research what has been offered? How to make sure that the person was informed? Until now being informed has been seen as central in order to make an autonomous decision. The personal contact in recruitment and informing process made it possible to check it. This process of informing took time, but was considered necessary if we value autonomy (autonomous acts, decisions, participation).
In order to look more closely at this new context of electronic informed consent the following case is analyzed in the presentation. Namely the situation when the participant gives an electronic signature to an electronic consent form without properly reading it. Does the current framework give us sufficient answers on how to proceed in situations like this or should this borderline case be governed by other considerations? Should we have such technological solutions to force one to read it? To check it (e.g. having a short test)? Or would it be ok to be of the opinion that if a reasonable grown up has decided not to care und trust blindly, then we should respect it?
It will be shown that the answer to the question differs, depending on which conception of autonomy to use. Therefore, choosing one and elaborating on the reasons for it will be the core issue of this presentation.

Ethical challenges in outpatient commitment

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Background: In Norway, the law allows the use of compulsory mental health care in both hospital and the community, when it is justified as the best solution for the patient and the environment. Outpatient commitment (OC) means a legal decision for compulsory mental health care even if the patient stays in his or her own home. For the patient it means having patient status in his or her own home, while receiving municipal health services. Mental Health Act regulates the use, monitoring and control of compulsory mental health care. The main criterion for using compulsory mental health care is that the patient must have a serious mental disorder as an active psychosis. The goal of treatment is to give patients help that provides improved health, promote independence, coping and user involvement. When you treat someone with OC, this affects the patient's autonomy and limits the ability to control their own lives. These principles are challenged by the use of coercion in treatment and impose difficult ethical choices between health care and society between securing patient independence while society has a commitment or desire to provide health care.
Aim: The purpose of this presentation is to discuss whether the use of OC can be defended ethically as a measure to help people with severe mental illness.
Method: The ethical discussion of the issue is based on the four core principles of health care ethics; respect for autonomy, beneficence and the principle of no harm
Results: Ethical values are fundamental to working with people, and the use of OC challenges and gives demanding issues related to ethical principles. Ethical issues require good decision-making processes. The concept of autonomy is particularly challenged by assessing the patient's consent competence. The principle of justice is elucidated through access to health services based on the patient's situation. Beneficence is based on the principle of charity and the principle of non-harm refers to how OC affects the alliance and trust in the health care service.

Conclusion: This presentation will point to ethical challenges using OC, and demonstrated how ethical practice has an impact on the experience of coercion and violation in patients with OC.

Anonymous donation in the ethics of transplant medicine
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From its beginnings transplant ethics has been founded on the ideal of altruistic giving. Accordingly, organ donation, has been operationalized in terms of anonymity to promote social solidarity and minimize the likelihood of trade in human body parts. The presentation will argue that so construed altruistic donation is conceptually defective and practically unproductive. To extent to which transplant ethics is based on altruistic giving, anonymous donation contradicts the characteristically human practices of giving and receiving. Thus, if transplants are to support social solidarity and curtail trade in human body parts, the mainstream ethics of organ donation needs to be replaced by one relying on a more adequate notion which responds to the practices of giving and receiving.
The argument will begin with an account of the key characteristics of the anonymous gift that is found in donation practices. These characteristics are social separation of the organ donor (or their family) from the recipient, their mutual replaceability, non-obligatoriness of donation, and non-obligatoriness of reciprocation on the recipient's part. It will be shown that these characteristics are also central to typical market relations, and so anonymous donation cannot promote social solidarity. Ironically, it may even serve as encouragement for instituting (regulated) markets of transplantable organs. In response to these difficulties, the presentation will offer a reframing of transplant ethics. Transplant ethics needs to be grounded in, rather than just support, the practices of giving and receiving known to human societies. The basis for such

reframing, is provided by the idea of sharing in another's misfortune, which relies on the human practices of giving and receiving. With suitable regulatory safeguards, the idea of sharing in the misfortune of another human being can provide a better conceptual basis for blocking market exchanges of human body parts.

Ethical trade-offs in Digital Phenotyping for Mental Health

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Currently on the rise as a potential game-changer in early interventions for mental health, digital phenotyping can be utilized as a means to help detect and prevent poor mental health in young people. Recording and analyzing human-computer interaction, speech patterns, search history, and social media posts could facilitate the identification of young people at risk and promote early intervention. Considering the amount and quality of data that could be collected in this way, we could greatly reduce the number of people developing poor mental health.
However, a number of ethical issues entail this approach. Depending on what kind of data is collected, how much of it, when, where, by whom it is kept, and for what purposes, the price to pay for the possibility of early intervention may turn out to be steep. How should we approach scenarios where we need to balance the benefits of early intervention against the risks and potential harms of mental health data collection and processing?
In this paper, I first explore the phenomenon of Digital Phenotyping, and the technologies enabling it. What does it mean have one's mental health evaluated through online behavior and technology interaction? How does it affect the possibility of early intervention in mental health? I then dissect some of the ethical issues that have been raised about relevant technologies and interventions, and some that arguably should be raised about the same. I highlight that the core problem may not be that values are at stake, but rather that it is difficult to understand, calibrate, and make decisions based on those values in this context. This puts decision-makers – be they patients, medical professionals, or legislators – in a rough spot: how can we decide which values and valuables to prioritize, if we do not understand the ways in which they are at stake in the first place? Lastly, I sketch an approach to medical decision-making with which we may be able to tackle this problem.

Addressing pollution from antibiotics production through institutional systems in high-income countries: ethical tensions and trade-offs

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Antibiotic resistance is widely recognized as a major threat to public health worldwide. Recent studies have found that one important contributor to resistance development is pollution from antibiotics manufacturing, typically in middle-income countries such as India or China. Several approaches for addressing this problem have been proposed by scholars, NGOs, government bodies, and the pharmaceutical industry. Using Sweden as an example, this paper considers the role of institutional systems that control the distribution and use of antibiotics in high-income countries (e.g. systems for authorization, generic substitution, public subsidy, and public procurement of drugs) in this effort. We identify a number of opportunities for key actors in these systems to influence industry to move towards more sustainable antibiotics production. However, we also show that each alternative creates tensions between this goal and other weighty objectives of these institutional actors, such as securing access to effective antibiotics

and keeping societal pharmaceutical costs down. Ethical judgment is needed to adequately deal with these tensions, and we provide an analysis of the central normative considerations at stake. In particular, we focus on the question of how decision-makers should weigh the short-term local burdens involved in tackling antibiotic pollution against the potential long-term global benefit of slowed resistance development. We argue that there are strong principled reasons for prioritizing the latter consideration. However, we also suggest that translating this principled stance into policy faces significant pragmatic challenges.

Choice, Health and Reason of State

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In this paper, I explore a philosophical problem concerning personal freedom in relation to the state, within the sphere of health. I will argue that the regulation of the bodies of citizens in terms of health in modern states poses a problem and a paradox. The problem arises from the choice citizens are facing on the regulation of their bodies. The paradox concerns freedom.

In the modern world, the rising importance of the body, both for society and for the individual has been documented by many researchers (Turner, 1982). Some, like Antony Giddens, have emphasized social trends leading to a personalization of control over the body, which he conceptualized as the 'body as a project' (Giddens, 1990). Others have focused on the growing centralization of body management at the hands of the state (Foucault, 1975; Skrabanek, 1994; Rose,1999;). Giorgio Agamben has suggested that life of the citizen is itself now getting politicized as it has become one of the political rights the state is supposed to provide one with (Agamben, 1998).

Historically, health became connected with the politics and social policies of 'healthcare' during the last two centuries as the liberal state gradually developed social services. The aim of these services is to extend liberty from formal (vote freedom of speech) to substantial rights such as access to healthcare. Universal healthcare as a social policy corresponds then to a right to health on the part of the citizen. From the point of view of biopower, this means that the citizen in evaluating her own body, and her future health prospects, has already entered a political field: for the *right* to health means that health is not private, in the sense of indifferent to the state. The state enters a relation with the citizen in the sphere of health, which means that the citizen in showing concern for its health is *also* entering a relationship with the state.

If one then steps back from this description of the liberal state and thinks in the tradition of Agamben about sovereignty, one may note that it has been argued that the king's body as a sign of sovereignty in democratic modernity becomes transferred unto the citizens of the nation in modernity (Santner, 2011). Hence each individual citizen body is a parcel of sovereignty. In this situation, where the citizen is formally bound to the state with its very physical existence, one can say that the access to choice over one's own health is not really *independent*.

For if the state to which I am bound acts to promote my health, if I am also contributing to this goal, I merely participate in the state's own reasoning. I contribute to the reason of state, which consists in maximising health and productive quality of the citizens while minimising costs for hospitals. Thereby my own freedom, which must also include the possibility of not agreeing with what the state prescribes becomes defined in such a way that I can only demonstrate my freedom by actively destroying my own health.

This is a forced choice, which is perverse because self-determination then takes the form of self-destruction.

Money for monitoring: the ethical challenges posed by data-sharing with health insurance apps

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As population is ageing and people's expectations in terms of health are also growing, rationalising healthcare expenditure is a major challenge for societies. In this respect, in several nations there have been different initiatives to improve population health and secure the sustainability of healthcare systems. Many of these initiatives have the aim of incentivising the adoption of positive lifestyle choices that can help to reduce the burden of some diseases. These range from merely informative campaigns, such as brochures about the effects of alcohol consumption, to more coercive measures, such as smoking prohibitions in some public spaces. In many cases, health-promoting initiatives also include reward-based programs, whereby individuals get either a cash benefit (e.g. a discount on the health insurance premium) or in-kind benefit (e.g. priority in waiting lists), if evidence is provided that they follow desired health-related behaviours. In this framework, the development of digital health devices capable of monitoring such behaviors has opened up entirely new possibilities. These devices can translate health-related choices – such as the daily steps or dietary habits – in analysable individual data, which can readily be used to monitor the quality of peoples' lifestyle. As a consequence, a number of apps have been created – in particular by health insurers – that offer direct economic benefits to those customers who accept certain aspects of their everyday behaviour to be monitored.
In this contribution, we will address this topic by presenting the results of a study where we analysed the features of programs offered by health insurance companies in Switzerland that provide economic rewards to users who share their lifestyle data through specific apps. To begin, we sketch out the basic features of these apps, such as the lifestyle habits they record, the rewards that they offer and the conditions to register. Thereafter, we tackle three ethically relevant questions that concern the provision of economic benefits in exchange for sharing personal lifestyle data. First, we illustrate differences and similarities between the provision of economic benefits through health monitoring apps and through other reward-based programs (e.g. performance of medical check-ups). Second, we question the extent to which offering economic benefits in exchange for the permission to monitor behaviour interferes with individual autonomy, since participation in these reward programs is generally free and voluntary. Third, we investigate whether it is desirable, from a societal perspective, that lifestyle is monitored to determine which individuals should be favored – at least in economic terms.

Are Organ Donors Really Dead? Brain Death and Personal Identity

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For many centuries, the permanent cessation of heart and lung functions had been the criterion of death. When one of these functions was lost, the other would follow immediately, and after some minutes had passed without the heartbeat spontaneously recurring, the individual was declared dead. This criterion seemed to be unequivocal. In the middle of the twentieth century, however, the advent of artificial ventilation began to call into question this heretofore deeply-entrenched understanding of death. In 1968 the Harvard Ad Hoc Committee proposed a new definition of death that quickly became the standard in many countries: brain death.
The concept of brain death has been controversial ever since its induction. Is brain death indeed our death? An answer to this question is not purely medical in kind, but presupposes that we

solve a philosophical problem which has often been neglected in the bioethical literature: what are we fundamentally, and to which anatomic locus does our concept of personal identity refer? Both, those who advocate a biological theory of personal identity, like animalists, and those who endorse a psychological account, like Lockeans, have something to say about brain death – albeit for different reasons. The brain is the organism's most important control centre. When it is destroyed, animalists may hold, the individual has died. Proponents of psychological accounts, on the other hand, usually stress the fact that the brain is the locus of consciousness and the organ in which mental states are stored.
In this paper, I investigate whether brain death can be our death vis-à-vis these different accounts of personal identity. I approach this question by combining philosophical theory with empirical data, analysing actual medical cases like the persistent vegetative state, brainstem stroke, dementia, or locked-in syndrome, in which some relevant brain functions are absent while other functions persist. This permits one to determine which characteristics of the brain are important to our survival – and which are not.
I will conclude that the functioning of both the brainstem and the cerebrum is a prerequisite of our diachronic persistence on those psychological accounts that highlight the capacity for being conscious; the Lockean accounts of personal identity, however, do not require an intact brainstem as the possession of mental states does, in principle at least, solely depend on the integrity of the tissues of the upper brain, provided only that they can be oxygenated. I shall also show that in the light of the extensive external life support available today, animalists should not accept any variant of brain death as the death of an organism. Finally, I will sketch five ways in which these findings have the potential to impact on the current practice of procuring organs from brain-dead donors.

Wearable and trasparency strategies
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Information and Communication Technologies (ICT) have a wide impact on medicine. ICT have changed the way in which medicine is practised and taught. Technology, integrated with health tools, is becoming a very popular trend within the healthcare industry and is increasingly being used on a more regular basis. Many of the wearable devices are providing data that can be used to inform both personal and clinical decisions. Indeed, wearable devices can help physicians analyse data for screening, diagnosis, treatment and even prevention of diseases. Thanks to them there is also a cut in time, space and costs. Moreover, wearables are connected to each other, share information and eventually promote positive health outcomes. Individuals will use and trust wearable technology to proactively achieve well-being and to manage illness. The strength of wearables is the ability to make the body transparent: they collect, gather and monitor user data to compare them objectively.
Taking into account the thought of Korean philosopher Byung- Chul Han about digital society as a society of transparency and its psycopolitical fallout, the paper examines the possible outcomes of health self-monitoring as a tool to improve and optimize the human being.
Monitoring becomes control, and together with transparency, carriers of a neoliberal logic, in which body health parameters become part of a wider strategy to maximize life expectancy.
In a society of transparency, life becomes a measurable, comparable and improvable algorithm and the self-transparent becomes a synonym of self-performance because of a voluntary self-exposure, an overabundance of information and its full exploiting. At the same time, controversially, life becomes meaningless, beacause it is geared to maximising profits.

The subject becomes a tool to reshape and reconfigure society by persuading the self to adopt mass behaviour, eliminating individuality and otherness.
The continuous follow-up and the constant ingoing and outgoing of information create a model of wellness and promote some prototypes of life. Fitness is still central in people's life, but it is conceived as a need of the subject to adapt themselves to the society of wellness and performance.
The transparent body, in this perspective, is the symbol of ICT pressure on medicine and of the underlying power of the medicine on the subject.
This paper aims to foster and promote reflection and analysis which are intended to make a constructive contribution to answering the ethical and political questions associated with the adoption, use, and development of ICT in medicine. Moreover, it explores how wearables might break beyond health and wellness scenarios and cover more diverse aspects. The risk is that medicine will lose its epistemic boundaries and will become the power that permeates the mind through the body: behind biomedical evolution lies the disapppearance of privacy, homogenisation and the collapse of the self as an individual. The search of perfection and performance expectancy will lead toward a performative society, changing people's lives and overcoming *omnes et singulatim* behaviour, reducing the autonomy and diversity of the subject.

Metaphysical Realism as a Cure for Chronic Cases of Medical-Ethical Fuzziness
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This paper attempts to clarify and defend a metaphysical realist perspective on the nature and ethics of medicine with respect to other human activities which overlap with it. I argue that the normative nature of medicine grounded in its real essence should serve as the primary guide for ethical reflection and ethical decision-making regarding the "fuzzy" edges of medical ethics.
First, I offer a brief argument for ontological realism about the nature of existence. I offer several reasons to think that existence is essential exemplification. These reasons are found in rational reflection on both sense experience and a basic experience of ourselves as rational beings.
Second, I argue that since all things which exist are things which exemplify an essence, and since medicine exists, it follows that medicine exemplifies an essence.
Third, I argue for the reality of a natural purpose or *telos* to medicine by defending the following argument: All things with essences have a *telos*. Medicine exemplifies an essence. Therefore, medicine has a *telos*. If something has a *telos*, then the *telos* is either natural or artificial. Medicine has a *telos*. Therefore, the *telos* of medicine is either natural or artificial. The *telos* of medicine is not artificial. Therefore, the *telos* of medicine is natural.
Fourth, I argue that the goodness of medicine flows from the realization of its *telos*. I offer reasons to think that the realization of a natural *telos* is an actualization of the goodness of the thing with that *telos*. Therefore, the realization of the natural *telos* of medicine is the actualization of the goodness of medicine.
Fifth, I consider human enhancement as a chronic "fuzzy" case of medical ethics. I argue that an activity which overlaps with medicine either hinders, helps or neither helps nor hinders the realization of the natural *telos* of medicine. Therefore, since the realization of the natural *telos* of medicine is the actualization of the goodness of medicine, it follows that any activity that hinders that good will not be a good act with respect to the goodness of medicine. Any act which helps to realize the good of medicine will be a good act with respect to the goodness of medicine, and any act which neither helps nor hinders the realization of the natural *telos* of

medicine should be considered good on its own merits and possible consequences to the *telos* of medicine.
Sixth, I conclude the paper with reflections on the idea that the ethics of medicine grounded in the natural *telos* of medicine should supply the guiding principles with medicine's relation to overlapping human activities which appear as the "fuzzy" edges of medicine.

Lived experience of Hereditary Chronic Pancreatitis: between biographical contingency and biographical disruption

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Background: Hereditary Chronic Pancreatitis (HCP) is a genetically determined condition with a constantly changing character that has substantial psychological and social consequences for patients and their families. Due to the variability in the clinical appearance, this chronic disease has no 'fixed image'. Little is known so far about the lived experiences of individuals affected by HCP. Drawing on the concepts of biographical disruption and biographical contingency, this qualitative study examines the viewpoints of HCP patients and their relatives to understand the character of the disease and to identify the social and ethical implications related to it.
Methods: Semi-structured qualitative interviews with HCP patients and their family members were conducted. Themes of the interviews are the patient biography, genetic testing, patient self-help groups and participation in biomedical research. Data were analyzed using qualitative content analysis, including inductive and deductive development of codes.
Results: Twenty-four adults were interviewed. Four major categories emerged: (1) Unpredictable clinical course of HCP; (2) HCP as devastating experience; (3) HCP as part of a normal and healthy life; and (4) being reduced to HCP. Unlike the concept of biographical disruption, the concept of biographical contingency includes the first three dimensions and can, therefore, serve as a theoretical model to explain HCP patients' experiences. In addition, pathologization emerges as a significant ethical issue in the context of living with HCP.
Conclusions: Our results can raise the awareness on the various facets of HCP. However, further qualitative research on patients and family members' experiences is needed to better understand the social and ethical implications resulting from HCP as a chronic, but constantly changing condition. Pathologization as an ethical issue is potentially relevant to other chronic conditions which are unpredictable in their clinical course.

Protecting the Best Interests of the Future Child in the Regulation of Gene Editing Technologies

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New reproductive technologies present significant challenges for legal regulation. As in all fields of cutting-edge technology, the challenge is for law to allow new technologies to flourish, while adequately regulating human behavior to protect fundamental rights and ethical standards. Framed in rights terms, the key conflict that arises is between the autonomy of commissioning parents, and the welfare or best interests of any child born through the use of reproductive technologies. The 'best interests principle' is a core tenet of international human rights law in the field of children's rights. It is protected by the United Nations Convention on

the Rights of the Child (Article 3, in particular), and is increasingly accepted by the European Court of Human Rights as a central aspect of the protection for children's rights under the European Convention on Human Rights.
Though the best interests principle is widely accepted as an organizing principle in the regulation of reproductive technologies, its use is theoretically problematic. Drawing on the work of Derek Parfit, and his identification of the 'non-identity problem' (Parfit, *Reasons and Persons,* (OUP, 1984)) leading commentators argue that the best interests of a future child are served in virtually all cases by allowing that child to be born. Therefore, it is argued that the best interests principle has no place in limiting the autonomy rights of commissioning parents, unless the child would inevitably have a life of absolute misery, a life "not worth living." (See, for example, the work of I. Glenn Cohen and J. A. Robertson).
This paper will examine the best interests principle in the context of groundbreaking new advances in human gene editing and the development of CRISPR/Cas9 technology. In November 2018 Chinese scientist He Jiankui announced the birth of twin girls with genomes edited to prevent them being able to contract HIV. The best interests principle is central to an ethical analysis of this remarkable scientific development. This unexpected and controversial use of CRISPR demonstrates that there is an urgent need for policy makers to grapple with the philosophical and practical challenges of CRISPR with a view to crafting responsible regulation.
This paper will interrogate the rich scholarship on the role of the best interests principle in the regulation of reproductive technologies and apply it to the dynamic new context of the use of CRISPR in the reproductive setting. The paper will begin by defending the role of the best interests principle in the regulation of all reproductive technologies, but go on to argue that even if the best interests principle faces conceptual difficulties in the context of established reproductive technologies, those conceptual hurdles do not exist in the case of gene editing. The paper will argue that the protection of the best interests principle in the regulation of CRISPR is essential to maintaining effective regard for fundamental rights in the development of this new technology.

Body Modifications for Gender Expression and Why the Blurry Boundary between Health and Wellbeing May not Always Matter
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In the shift from 'gender identity disorder' to 'gender dysphoria,' psychiatry has in effect ceded that people do not need male-typical bodies or female-typical bodies to participate in female and male gender identity respectively. For all its value in depathologizing atypical gender expression, that conceptual move has not answered all questions regarding the healthcare of transgender people. Among the questions now at issue is coverage of the costs of body modifications important to the expression of a gender identity. To what extent are government providers of healthcare and private insurers obliged to cover the costs of the body modifications wanted by people to shape their bodies in conformity with their gender identity? Government-sponsored healthcare reflects, of course, decisions made through legislative processes, so coverage for this kind of treatment is not uniform across the world, to say the least. For their part, private insurers usually have broad latitude about what clinical interventions they will pay for, unless coverage is specifically mandated by law. In general, both public and private insurers do pay for some treatments to modify the body but not all, such as facial feminization interventions. Yet in one sense, it is possible to conceptualize facial modifications as necessary in the treatment of gender dysphoria, on a par with mastectomy or genital modification. In

another sense, it may be wondered whether the interest in these kinds of body modifications is better conceptualized as enhancement. On the former view, there would be a presumptive responsibility for covering these kinds of interventions, either by paying for them outright or subsidizing them to some degree. On the latter view, there would be no obvious reason for health insurers to extend coverage to what are simply aesthetic preferences. An alternative way to approach the matter is to interpret the treatments in relation to their meaning for social equality. A transwoman who – despite mastectomy – does not appear 'female' in a socially conventional way may be unable to participate fully in social goods that are stratified according to social expectations of femininity. Along the same lines, some transmen may face obstacles to social goods stratified according to gendered expectations of masculinity because of traits coding them as female. Certain body modifications may be important, this is to say, to ensure the appearance that functions as the threshold of access to gendered social goods. In this sense, concern about maintaining a strict boundary between medicine and enhancement may ultimately be subordinated therefore to the demands of justice, in helping protect access and equity to goods stratified – rightly or wrongly – by gender. This means, of course, deploying financial coverage to ensure healthcare understood in terms of equality of opportunity. Seen this way, it is plausible to make a case for extending coverage to facial feminization and other body modifications that trans people may need to secure goods that are socially stratified by gender.

Personalized (PM) medicine, expertise and trust

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Health services have been a primary arena for asymmetrical trust, i.e. a trust based in an uneven power-relation where the trustor is dependent on the trustee. Over the past decades, this has changed dramatically with an increased focus on the standing and rights of the individual, the patient, in these relationships. PM fits well in with this development as an extension of the emphasis on the role of the individual in her/his health, disease and well-being.
PM is characterised by increased production of data points, increased access to data points, increased reliability of findings with an ensuing increased tailoring of diagnostics, treatment and prevention. The ideal is to minimize the layer of interpretation and translation between relevant health information and the patient or user. Arguably, this opens for a new level, maybe even a new form, of autonomy through increased participation in treatment and prevention, and by that, increased empowerment of the individual. The other side of this coin is reduced expert power and reduced paternalism of the kind associated with the traditional doctor-patient relationship.
Taking a closer look at the empirical realities of the promised PM empowerment reveals a murkier landscape. It is true that the new –omics tools provide a better, more detailed picture, but at the same time this picture is more complicated, and – at least in a transition phase – disturbed by information 'noise'. PM is an interdisciplinary endeavour and relies on a number of complementary areas of expertise. This is a source of increased opportunities, choices and involvement – for good and bad. At the same time, many of these expert tasks are replaced by technology through automation, increasing reliability and seemingly better accessibility while the source and logic of interpretation is more hidden by the layers of required technologies.
So how does this affect trust – or how *should* our trust in health services and expertise be affected? The main reason why this is a relevant question, is that the PM regime is obscure, especially the issue of responsibility. Who is responsible for the diagnosis and treatment, when

there is no core expert? For a PM user, the trust must be distributed. There are many sources of information, interpretation and knowledge and many experts – human and non-human alike. As patients in need of help we will still be vulnerable in the future, and many of us will lack the capacities for replacing trust with self-determination. We will still need help to interpret information and to make informed choices. Some will prefer advice from an expert with knowledge and experience. Others will still want directive guidance and not be burdened by the added responsibilities self-determination will give in difficult situations. However, the basis for trust will be altered, due to the distribution of responsibilities and use of technology. We will explore a Kantian approach to handling this turn from a more or less 'blind' trust to reflexive trust.

Capabilities and Genetic Enhancement in Sport

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Recent developments in gene editing technology leave no doubts, that the era of humans with edited genomes is already there. Also, it might be reasonably predicted that as soon as the technology will be proven to be safe in medical context, it will be used in sport to enhance the physical and may be also psychological abilities of athletes. Consequently, the question about permissibility of genetic enhancement in sport becomes inevitable. Recently Roduit & Gaehwiler proposed an ethical framework for evaluating permissibility of enhancement in sport. According to their view, when considering the enhancement of athletes, the underlying question should be: "What does it mean to be human?". They argue that sport is interested in comparing the best human athletes and not the best athletes in abstract. Moreover, they claim that the best account of what does it mean to be human is captured by the capabilities approach put forward by M. Nussbaum. However, in my paper I will argue, that, unfortunately, this approach to human enhancement in sport is misguided. First, Roduit & Gaegwiler wrongly assume that Nussbaum's capabilities approach is an anthropological theory. Second, their account is based on misinterpretation of important concepts used by Nussbaum. And last but not least, I will argue that the question about what does it mean to be human is hardly relevant in considering genetic enhancement of athletes. I will end with some positive suggestions towards an approach that might be used to evaluate enhancement in sport.

Reproductive Medicine in the United States, Women's Rights, and the Ragged Edge of Legal Personhood for the Unborn

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Ethical opposition in America and to behaviors of pregnant women that could harm their fetuses is most commonly grounded in the claim that they are moral persons who have fundamental rights to life and bodily integrity or possess another kind of moral status that confers these rights. However, the U.S. Supreme Court has expressly ruled that fetuses are not constitutional or legal persons, i.e., they lack constitutional rights to life, liberty, or property and are not entitled to equal protection of the laws. Nevertheless, government agents–often with the aid of medical clinicians–have taken action against pregnant women (who undoubtedly are constitutional persons) that ignores their rights in order to vindicate the State's interest in protecting the unborn.

Four categories of government action against pregnant women for causing fetal demise or harm can be identified: 1) criminal prosecution based on the application of laws protecting children such as child abuse and medical neglect; 2) prosecution based on laws that pertain to persons generally; 3) prosecution based on women's violation of feticide statutes; and 4) forced medical treatment and involuntary civil detention of pregnant women. For example, women have been prosecuted for homicide by child abuse who experienced a stillbirth claimed to be the result of their use of illegal drugs. Others have been forced to undergo surgical delivery to protect their fetuses or involuntarily placed in State custody when they voluntarily sought medical help for drug dependency.
Although medical information is made confidential by various privacy laws and professional ethics, in many cases the information used by law enforcement that led to the arrest, detention or forced treatment of pregnant women was voluntarily disclosed by the attending medical clinicians. These disclosures have commonly been made in the absence of a court order or statutory authority. Moreover, physicians and others have performed judicially sanctioned (but not required) medical procedures on non-consenting women, a prima facie unethical act. Evidence exists that hospitals and their clinicians who have participated in detaining pregnant substance abusers have then failed to provide them with suitable treatment.
Clinicians should not breach confidentiality or perform such interventions. Laws pertaining to "children" or "persons" cannot properly be interpreted to include the unborn. Therefore, pregnant women who ingest substances or who behave in a manner that may be harmful to fetuses cannot violate child abuse or endangerment laws. While legislatures may have the constitutional authority to enact laws prohibiting women from intentionally killing or harming their fetuses outside of a legal abortion, they may not prohibit such conduct if it is unintentional. Prosecution for negligent conduct would violate women's rights to liberty and due process. Only legislatures may grant fetuses legal protections as this is a policy decision reserved to the democratic process, and they may decide to grant only some (e.g., postviable) fetuses protection. Clinicians go beyond the appropriate boundary of good medical practice when they violate pregnant women's rights in order to protect fetuses when the law does not actually sanction such behavior. Moral disapproval alone is insufficient.

New offers of direct-to-consumer genetic testing and new ethical problems
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A variety of health-related genetic tests is currently advertised directly to consumers. The tests employ new approaches (whole exome and genome sequencing), may report on a wide range of conditions, and are targeted at new groups such as (prospective) parents (carrier testing, preconceptional and prenatal testing, testing for children). Furthermore, third-party web-based genetic data interpretation and sharing services are available to DTC GT consumers (who have their genomic data downloaded in the required format). Some of the platforms may offer payments for consumers for sharing their data. The currently salient ethical issues related to the offer of genetic testing and services include, among others: questionable analytic and clinical validity of the tests, adequacy of informed consent and pre-test counselling, potentially misleading advertising, the offer for children and reproductive purposes, research uses and commercialization of consumers' genomic data.

Medicine and human evil
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Medicine has the power to change the lives of patients and human persons to the better, and the acts of medicine are based upon trust, knowledge and human compassion. However, political propaganda, ideology and peer pressure can block compassion and corrupt the human core of medical professionalism. German physicians orchestrated and performed killings and genocidal activities as Hitler`s biological soldiers and physicians play a role in ongoing human evil and atrocities today. What may be the reasons for one of the professions we trust the most in caring for health and alleviating suffering to be involved in torture and killing of innocent civilians? The paper will address various reasons and factors that might lead to the moral corruption of German medicine during the Nazi area and will analyze how certain intrinsic factors of medicine, such as medical epistemology, medicalization, objectification and the "healing-hurting paradox" might dehumanize and lead to the moral corruption of medicine. Moreover, the paper will track certain tendencies in the political and social culture of today that might lead up to future disasters involving health professions and medicine in devastating and evil activities. Finally, I will discuss ways to strengthen the resilience of humanity and empathic character of future medicine.

Attitudes of Israeli Parents of Children with Down Syndrome toward Non-Invasive Prenatal Testing and the Scope of Prenatal Screening

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Non-invasive prenatal testing (NIPT) is a new and safe genetic test targeting fetal DNA from maternal blood. Due to its non-invasiveness, early utilization and increasing ability to provide abundance of genetic information, NIPT has reinforced social and bioethical quandaries concerning prenatal genetics. Exploratory findings based on 20 semi-structured interviews conducted in 2017-2019 with Israeli parents of children with Down Syndrome (DS), four of whom also serving as representatives of DS organizations, are presented regarding arguments pro and con NIPT and prenatal diagnosis (PND) in general; the social context of decision making about NIPT; and views on life with DS and termination of pregnancies on that ground. While illustrating the large heterogeneity of views concerning NIPT and PND amongst parents of children with DS, our respondents criticized the imbalanced information provided by professionals regarding DS, seen as sending a discriminating message and in line with the public ignorance surrounding DS. These views are further discussed in the multi-cultural context of Israeli society.

Pillo Health Digital Home Companion, Lowering Costs While Improving Outcomes: The Ethics Cost of Artificial Intelligence Home Medical Technology.

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There is a burgeoning development and manufacturing of medical devices and applications (apps) incorporating Artificial Intelligence (AI) technology. These innovative technologies offer support and assistance in the practice and delivery of medicine and healthcare in hospitals, in remote and home monitoring, and in care management. Pillo Health has just launched one such device; the Pillo health digital companion or Voice-Activated Home Health Companion. This apparatus enables medication management and care plan delivery by helping patients to

better adhere to medication regimens. It also provides them with research-backed care plans and important instructions at home to remain active and empowered in improving their health. Six in ten Americans live with one chronic condition, at least, and many of them find it difficult to adhere to their medications. It is estimated that besides a higher mortality rate in this group, about $289 billion is lost annually because of their non-adherence to medication. Thus, making it one of the leading drivers of healthcare costs across the U.S.

Pillo collects and analyzes real-time health data to extract valuable insights from inside the home and notifies the caregiver if the patient missed a dose of medication.

Other remote and home monitoring and care management robots also collect and analyze data which they dispatch to healthcare professionals and family members. Some of the information may reach the insurance company, which may be to the patient's detriment.

The often-stated goals of these technological innovations are to lower costs while improving outcomes, and to facilitate and support healthcare professionals to more efficiently execute their normal duties, especially in areas that involve large data manipulation and knowledge.

Although these technologies are filling the market, there is some reluctance in their being accepted. There are various reasons (including ulterior motives) for adopting or rejecting them. Both the often-stated reasons for the marketing of emerging remote and home medical technologies, as well as the doctor's own motives for adopting them, can be supported by utilitarian ethical principles -utility and benefits (the good outcomes).

However, employing the perspectives of other ethical theories such as ethics of care, this study interrogates these often-stated goals, contending that while the in-home AI technologies produce the above-mentioned benefits, they do not deliver and will never replace human interaction or the human touch (compassionate care) which is paramount to care. Likewise, their use can blur the line between people and instrument, limit privacy and confidentiality, and interrogate our conscience. Because AI technology employs machine learning and training, it is often susceptible to bias which can unfairly impact the patient and health outcome. There is, of course, the issue of equitable access and affordability.

In conclusion, we argue that there is a need, therefore, for tighter regulations and supervision to align with and attend to the ethical issues raised above. There is also a need to minimize and manage both the machine bias and its possible negative impact.

The Wives of the Tuskegee Study: An Untold History

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The Tuskegee Study of Untreated Syphilis, conducted by the Public Health Service (PHS) between 1932 and 1972, is one of, if not the most, infamous cases of medical malfeasance in the history of the United States. During this nontherapeutic study, poor black men from Macon County, Alabama, were observed by physicians and public health officials with the objective of studying the natural course of untreated syphilis. The men, never told they had syphilis, received medical care and a burial stipend in exchange for their participation. The Study has been profusely written about by historians, and rightly so. However, there is one group who seem to be absent from both the Study itself and its subsequent history: the wives of the men of Tuskegee.

As a sexually transmitted disease, untreated syphilis quickly spreads from one sexual partner to another. Sadly, like other diseases, it can also be spread from mother to child. As the men of Tuskegee were never treated, their wives bore the brunt of the burden of the disease, suffering horrifically in their own bodies and bearing children with congenital syphilis. Moreover, as unofficial subjects of the Study, the wives were denied even the basic medical care and burial

stipend afforded their husbands. The Tuskegee Study, in which the wives were targeted in an even more brutal, if less direct, manner than their husbands, is but one study in a long history of experimentation on black women's bodies. Why then, do the wives go largely unmentioned in history? The aim of this paper is to explore the historical, political, and social context that fed this cruel exploitation of black women's bodies, and to demonstrate the incredibly damaging ways in which these attitudes continue to impact the treatment of black women today by both society at large and academia.

The medicalization of appearance: Cosmetic medicine is neither medicine nor ethically acceptable practice

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What we will here call cosmetic medicine (including surgery) constitutes a burgeoning and highly profitable practice performed by medical professionals using technologies to alter the appearances of previously healthy people. We here firstly argue that this practice generally is not congruent with the goals of medicine as commonly understood and, secondly, that it is ethically unacceptable as it harms health through individual side-effects and by breaking down bodily acceptance and concepts of normality.

Is cosmetic medicine medicine at all? As commonly defined and understood, medicine as a profession is defined by the goals of curing, alleviating and preventing of disease and maintenance of health. Cosmetic medicine follows another goal, namely to, at any given time, "enhance" or alter the appearances of healthy individuals according to particular cultural ideals. Based on this descriptive divergence of goals, we argue that cosmetic interventions cannot be regarded as medical practice. If it is to be regarded as medical practice, honest definitions of medicine should be changed to include the goals of cosmetic medicine.

Is cosmetic ethically justifiable practice that does more good than harm? Empirical evidence shows that body image-pressure above a threshold is unhealthy and that there is a growing incidence of this unhealthy pressure. We argue that the possibilities offered and actions of medical professionals performing cosmetic interventions is a necessary condition for and part of a causal dynamic which breaks down concepts of normality. Through the mechanism known as "supplier-induced demand" they are raising the bar for what is considered normal or good enough and actively narrow the definition of what is considered a normal appearance. Instead of defending normality, they actively define an "imperfect" bodily appearance as a medical condition. While we acknowledge that there are many drivers of cultural ideals, this *medicalisation of appearance* allows the field to create a market of bodily dissatisfaction, which is a form of unhealth. We argue that this, on a societal level, is to cause harm, and that these clinicians thereby violate one of the most important ethical principles of medicine.

Purveyors of cosmetic interventions often claim that there is empirical evidence that cosmetic treatments offer health benefits to individuals. We argue that the evidence is tenuous and that improvements in self-esteem and quality of life is often short-lived. Most fundamentally, we argue that, to extent that cosmetic medicine satisfies patient needs this happens after this practice has contributed to creating the same dissatisfaction and needs. The benevolent acts claimed by cosmetic practitioners cannot be separated from the malevolence they have previously caused and are causing through the same practice.

The field of cosmetic treatments highlights the need for a much-needed debate on professionalism in the field of medicine and for the individual physician.

Patient involvement when facing severe mental illness and coercion - A qualitative study
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Objectives: The use of coercion is common during severe mental illness, yet controversial. The patient may lack competence to consent and be in urgent need of help. Patient involvement can be perceived as idealistic, futile or even harmful by the professionals. Research on what patients subjected to coercion actually wants when it comes to involvement is limited but may be important to improve mental health services. Thus, we wanted to explore the views on patient involvement among people with first-hand experiences of being coerced during severe mental illness.
Methods: This study includes semi-structured focus groups and individual interviews with 24 participants who had various severe mental health problems and experiences with coercion. Data were collected in 2012-2013 in three regions of Norway and analyzed by a thematic content analysis.
Results: Many of the participants described inadequate involvement and information, in particular within the hospital services and when medication was given. All participants wanted the professionals to be more responsive, acknowledging and curious towards the patient's own perspectives. The participants had several suggestions on how to realize this, for example always ask what the patient regards as the main problem, and the patient's experiences with past treatment. They also wanted closer follow-up during and after the use of coercion. Furthermore, the participants emphasized balancing evidence with an individual approach, extra caution when evidence is weak, using the least intrusive methods, giving higher priority to clinical communication, better involvement of family and peers, more use of decentralized services, and greater use of user-experiences in the health care organizations. Rich examples on what was missing and concrete suggestions on how to realize the potentials for improvement and balance different moral principles were provided.
Conclusion: This study indicates that patients and users regard patient involvement as important also when coercive measures are used or considered, and that it may have the potential to improve and reduce the use of coercion and create better treatment and decision-making processes. The results may also be relevant for clinical ethics support services and legal amendments.
Research support: The study was funded by the Norwegian Directorate of Health.

Human intelligence and artificial intelligence: which cooperation and ethical implications?
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The arrival of digital research, where the object of research is transformed into numerical data, makes it possible to study the world using new epistemological paradigms. What matters now is only the correlation between two quantities of data, with no concern for any consistent theory that explains such correlation. Today these correlations are used to predict with acceptable accuracy, even with no supporting scientific theory, the risk of asteroid strikes, even by ones that are unknown, in various locations on Earth, the locations at risk of terrorist attacks, the voting in United States presidential elections, and short-term financial market trends.
What is seeming to be the outcome of this *new revolution* is the dominance of information, a conceptual labyrinth whose most common definition is based on an equally problematic category—*data.*

The technological evolution of information and of the world seen as a series of data takes its concrete form in *artificial intelligence* (AI) and in robots. We are now able to construct machines that can make autonomous decisions and coexist with man. It is enough to think of the driverless cars that Uber, the well-known private car service, already uses in some cities, Pittsburgh for example, or radiosurgery systems like Cyberknife.
Contemporary society presents extremely delicate challenges where the most important variable is not intelligence but rather the little time available in which to make a decision. Here, cognitive mechanisms can have important applications.
At this point a whole series of ethical considerations presents itself with respect to how the mechanism's cognition can be validated taking to account the speed of the response that is sought to be made possible and achieved. Still the greatest danger involved is not robotics or AI, but rather ignorance of the technology and adoption by management that is not at all trained in it use.
If the near future—actually the present—brings us cooperation between human intelligence and artificial intelligence, and between humans and autonomous robots, we need to try urgently to understand how the participants in this mixed reality can coexist.

The end at the beginning: consideration of end of life decision making in ventilator independent neonates with ultrashort gut syndrome'.

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Gastroschisis is a relatively common neonatal condition. Whilst alarming for prospective parents, it is usually an isolated defect, and, after the initial surgical closure is performed, then infants generally have a good outcome, with the overwhelming majority surviving.
However, when complications develop the results can be devastating and pose significant ethical issues, as the case of infant R illustrates. R was born at term with an antenatal diagnosis of gastroschisis. His parents were well informed about the condition and understood that he would require surgery. However, at delivery his bowel was found to be severely compromised. R was immediately taken to theatre in order to try and save his bowel. However, this was not possible, and the vast majority of his small and large bowel was removed. R returned from theatre with only 4 cm of bowel left in total. This is physiologically devastating. It easily qualifies R as 'ultrashort gut syndrome' - a diagnosis that carries significant morbidity and mortality.
R's parents were left with a traumatic prospect. R would be reliant on long term intravenous (IV) access and intravenous nutrition (TPN) solution as he did not have enough bowel to sustain life himself. Long term IV access carries significant risk of infection. Long term TPN carries risk of poor growth, poor development and liver failure. Ultrashort bowel syndrome may necessitate a bowel and possibly liver transplant in the future in order to ensure survival. R's parents loved him deeply but questioned whether this course of treatment was ethical. Was this life really in their child's best interests? Or was it more appropriate to reject this conventional management plan and instead palliate him.
However, R had a normal heart and lungs. After the initial operation he quickly weaned off the ventilator and was able to breath himself, with no respiratory support. This raised the question that if R was to be palliated, what would the reality of palliation look like. Would it be justifiable to withhold nutrition solution to an infant, and have them starve to death? Withholding IV fluids is accepted in certain circumstances in adult palliative care - but does this remain acceptable when extrapolated to infants with different underlying physiology?

I would argue that whilst the prognosis from ultrashort gut syndrome is greatly improving, the diagnosis still carries a significant risk of mortality, and in all cases carries a significant burden of harm intrinsic to the treatment itself. Therefore, to my mind it is entirely reasonable for parents to question whether this is in their child's best interests. I think it can be argued that palliation in this situation is appropriate, and that the lack of dependence on a ventilator should not alter the approach to whether or not palliation is appropriate (This was an issue that had caused concern from several clinicians). In addition, I would argue that if we find it ethically acceptable to withhold IV fluids from adults in certain palliative circumstances, that it would also be ethically acceptable to withhold IV nutrition from a neonate with a palliative condition. Feeding via intravenous route is not physiological; it is a medical treatment. If a treatment is not in the patient's best interests, then it is not justified to administer it. Palliative care should instead focus on ensuring that individual is comfortable.
Decisions about quality of life are incredibly divisive and personal. In my opinion where there is a significant burden of treatment, even when there is a potential for increased survival, whether the course of treatment is in the child's best interests must be taken with huge emphasis on the parental perspective, as they know their child and they uniquely are the ones who will be living the outcome alongside their child. For well-informed, realistic parents who are welcoming of the full picture of information and implications of their decision, I believe parents are best placed to make the decision for their child. This position is supported with the legal precedence outlined in re T. (a minor) (Wardship: Medical Treatment) 1997. 1 WLR 242.
For R, the treating clinical team strongly felt he should commence TPN. His parents followed the advice of the clinical team.

The ethics of touch in a therapeutic relationship in physiotherapy

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The aim of the lecture is a comparative analysis of the axiological model of a therapeutic relationship in physiotherapy with the results of qualitative research on patients undergoing physiotherapy.
The ethics of physiotherapist's profession is a relatively new field of bioethical considerations. National and international codes of physiotherapists' professional ethics define ethical standards for the profession by referring to patients' rights and basic principles of bioethics and values common to all medical professions. Such documents are quite general in nature since they take into account five areas of physiotherapist's work: physiotherapist's practice in patient management, consultation, education, research, and administration.
The increasing number of bioethical works on philosophical and ethical aspects of human carnality in medicine rarely mention moral, emotional or psychological problems connected with physiotherapists' use of touch as a diagnostic and therapeutic tool. There is also a limited number of publications referring to ethical values which are significant for a therapeutic relationship in physiotherapy.
Physiotherapist's work with their patient's body requires entering another person's sphere of intimacy. Touch has not only therapeutic but also psychosocial meaning. Patient's attitude to their own body, culture -specific importance of physical contact, previous positive and traumatic experiences as well as age and sex of the patient all seem to be of high importance for a therapeutic relationship. Our "body memory" retains information about touch as well as emotional states which might occur during treatment. Through touch a physiotherapist may convey support and acceptance building an appropriate and, therefore, efficient therapeutic relationship. Touch may then fulfill the function of informal communication.

The aim of the lecture is to:

1) Present morally significant features of the physiotherapist-patient relationship which distinguish it from other medical relationships.
2) Outline the approved axiological model of a therapeutic relationship in physiotherapy, which will be verified through qualitative and quantitative studies conducted by an interdisciplinary research group consisting of a psychologist, sociologist, pedagogue, bioethicist and physiotherapists.
3) Present the methodological assumptions of the realized and planned empirical studies on physiotherapists and patients.
4) Analyze the initial results of qualitative research on patients' opinions concerning values which are particularly important in the relationship with a physiotherapist.

The work is the result of a research project no 2016/21/B/HS1/01824 entitled "Physiotherapy Ethics. Touch, Corporeality, Intimacy" funded by the National Science Centre, Poland.

The roles of solidarity in Philosophy of Health Care

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Until recently, in Bioethics there was little or no talk of solidarity. However, in the last years, articles based on the analysis of solidarity in relation to bioethics, especially in public health ethics, abound. Authors such as Rud Ter Meulen, Barbara Prainsack, Alena Buyx, Angus Dawson, Bruce Jennings, Marcel Vermeij, and others, are a token of this. The reason is that many public health actions may not be justified without appealing to solidarity. Think of vaccination policies, blood and organ donations, air, water and food control, universal health care, and global health. There is even talk of intergenerational solidarity, and with animals, plants and places (more-than-human solidarity). The four principles of traditional bioethics do not account for how and why such actions should be justified, including the liberal conception of justice, based on rights, personal responsibility and equal opportunities, but not on duties, social responsibility and equality of outcomes (e.g. reduction of health inequities).
In my proposal, I offer a beginning attempt to respond to Dawson and Verweij's call for greater "systematic reflection upon the idea of solidarity" and exploration "of its implication in moral theory and the justification of public health policies". Specifically, there is a serious problem I wish to draw attention. In the current analysis of solidarity in public health (e.g. Praynsack and Buyx's, Dawson and Jennings'), a problem arises: there is some muddle between the descriptive and the normative conception of solidarity, between the solidarity as motivation to act and solidarity as justification of an action, and between solidarity as a feeling and solidarity as a right. We have to avoid these confusions if we want to offer a useful idea of solidarity to face the challenges of solidarity in public health.

Maybe she's born with it, maybe it's epigenetics: Cosmetic enhancement and fight against lookism

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Ethicists have argued that lookism, discrimination against unattractive people, should be taken more seriously in philosophical debate and social, legal and medical measures ought to be taken to improve the quality of life of people affected by lookism. One possible way to fight against this type of discrimination is cosmetic enhancement: making people more attractive. With the

developments in epigenetic science, we now know that epigenetic mechanisms are crucially connected to our looks and ageing process. While our genetic code sets the stage for what makes our appearance unique, equally important is the dynamic layer of molecular information that lies above our genes – our epigenome. If we could easily enhance our looks by epigenetic beauty products, eating habits or behaviours could it help in fighting against lookism or ageism? I consider whether this new frontier of enhancement is a welcome trend and whether there is a moral case for cosmetic enhancement via epigenetic reprogramming.

Non-Invasive Prenatal Whole Genome Sequencing: Post-Birth Challenges

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Non-Invasive Prenatal Testing (NIPT)[1] is a technology that allows testing fetal DNA originating from the placenta through a blood test of the pregnant woman as early as 10 weeks gestation. With improving performance and decreasing cost, an increasing number of healthcare systems are currently implementing it for some conditions. Studies are now exploring its use as a screening test for all pregnant women for an expanding spectrum of conditions. NIPT can technically be used even to sequence the whole genome of the fetus (NIPW) and some have already argued in favor of publicly funding this use[2]. While most debates have focused on the impact of this technology on women's reproductive autonomy and on disability rights, this talk will explore the implications of NIPW in cases where the pregnancy is not terminated, but rather a child is born about whom the parents, and potentially the healthcare system, have vast amounts of genetic information.

Parents usually do not have the right to genetically test minors for conditions unless they are childhood-affecting[3]. The logic behind this norm is that the child's 'open future' needs to be protected and that testing decisions ought to be left to the individual later in life. This logic, if applied to NIPW, would mean that information that is not clinically useful during pregnancy or childhood should not be disclosed to the pregnant woman. However, women (and their partners) may wish to make termination decisions based on information that is related to late onset diseases or increased risk. Moreover, in the context of pregnancy, the fetus has no rights to privacy.

On the other hand, some have argued that concerns about open future and autonomy are misguided, because knowledge of genetic information, even the whole genome, does not deprive a child of her open future[4]. Some have further argued that nobody possesses a 'right not to know' genetic information. If this logic is applied, then pregnant women should be allowed access to unlimited prenatal testing and as guardians of the child they have decisional authority regarding disclosure of genetic information to the child later on.

These two opposing approaches demonstrate that NIPW requires a new conceptual framework. The challenge is to balance the reproductive autonomy of the pregnant woman against the interests of the prospective child, while taking into account possible normative arguments regarding the nature of genetic knowledge, responsibility and autonomy. This talk will explore possible mechanisms that may support such a balanced approach and discuss their advantages and disadvantages.

[1] Now more often referred to as Non-Invasive Prenatal Screening (NIPS) or cell-free DNA testing (cfDNA)
[2] Chen and Wasserman. A framework for unrestricted prenatal whole-genome sequencing: Respecting and enhancing the autonomy of prospective parents. *American Journal of Bioethics* 17(1): 3–18. 2017.
[3] Deans, Clarke and Newson. For your interest? The ethical acceptability of using NIPT to test 'purely for information'. *Bioethics* 29(1): 19-25. 2015.
[4] Rhodes. Resisting Paternalism in Prenatal Whole-Genome Sequencing, *American Journal of Bioethics*, 17:1, 35-37. 2017.

Revisiting traditional male initiation in South Africa. A global bioethical perspective

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The theme of traditional human initiation and circumcision in South Africa receives widespread attention because of the deaths of a large number of Xhosa boys (and young men) in the Eastern Cape. The tension between the right to cultural practices and the right not to be harmed gives rise to the research question if the SA constitution is in line with global bioethical principles in this regard: can respect for cultural diversity be acknowledged on the one hand, but restricted on the other hand? Answering the question appears to be important in the South African context, because some traditional leaders question the view of cultural rights being weaker rights and deem cultural rights to bear more weight. The central theoretical statement of this study is that the SA constitution is in line with global bioethics as expressed in article 12 of the Universal Declaration of Bioethics and Human Rights by UNESCO.

What it means to respect a child's agency in a no-choice situation. The case of bone marrow transplantation between siblings

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We have conducted a qualitative empirical study on bone marrow transplantation (BMT) between siblings who were children at the time of transplantation. 17 volunteering families with such experience could be interviewed 0-20 years post transplantation. With each of the families we have conducted a family group interview to get insights on particular family dynamics and shared family narratives. This was followed by a set of individual interviews with all family members (82 interviews in total).[1] An analysis of the families' stories clearly suggests that once the family had been tested for HLA histocompatibility and a brother or sister had been found to be a potential donor, there was essentially no choice for them other than to proceed to the transplantation and to allow stem cells to be extracted from the body of the donor child. Depending on age, the child was asked before performing the stem cell extraction. But some donors and parents said that a refusal would in fact have been impossible or would have been overridden by the parents.

This raises ethical questions about the decision-making-procedure in such a situation. In particular: How should the child's agency be respected? I shall discuss four models that can be distinguished theoretically: (i) posing the burden of responsibility to the child and treating the child as an autonomous agent; (ii) respecting the child's autonomy half-heartedly by asking first but letting the child no chance to refuse ("fake autonomy"); (iii) not letting the child to decide but explaining later, step by step; (iv) promising a bonus ("bribe"); (v) explaining the child in an appropriate language before the operation, why the situation (i.e. the survival of the sick child) is demanding the BMT and why for the family there is in fact no other choice. In all these models, hearing the child's concerns and respecting the child's carings is key. But the models differ in how moral responsibility is constructed and distributed within evolving parent-child and sibling relationships. This case of BMT is discussed as a model case for other no-choice-situations in pediatric medicine.

[1] The research team included Madeleine Herzog and Dr. Martina Jürgensen; I was Co-PI with Professor Christina Schües. The empirical study has been conducted by MJ and MH and was linked to a philosophical study by CS. Funding was provided the German Ministry of Education and Science (BMBF) and Fritz Thyssen Foundation.

Cancer screening and the ethics of solidarity

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Critics of screening to prevent cancer argue their case in familiar utilitarian terms: many popular kinds of medical screening, considered in their broad effects, cause more harm than the benefit they offer. They acknowledge that their arguments often fail to persuade and explain this as the result of biases that stand in the way of the public grasping the magnitude and importance of screening-related harms. The same biases stand in the way of enlisting deontological ethics, in the form of improvements in the informed choice process, as a response to the harms of screening. For example, death from cancer is particularly salient, and the prevalence of cancer leads to an availability bias, while the medical harms of screening and its marginal benefits are not well-understood by the public and not experienced directly. In this paper I argue that this "deficit" model of the public understanding of screening is inadequate to engage with the full range of reasons the public have for supporting and engaging in screening. My goal is to evaluate normatively the solidaristic rationale for cancer screening.

Cancer screening is justified by two strategies: as individual risk management and as a social project of defeating or, in the language of public health, "controlling" cancer. Utilitarian criticisms focus on disputing utilities that individuals assign assigned the risk reduction, inconveniences, and harms of cancer screening and fail to grapple with the importance to the public of a commitment to a shared, longterm project of cancer control.

In this paper, I develop an alternative understanding of public support for cancer screening as a solidaristic project. I evaluate two possible solidaristic rationales for cancer screening: as a form of political solidarity (the call of a disadvantaged group for support and voice) and as a form of social solidarity (a shared project for the benefit of all). Cancer control is best understood as a solidaristic project at the boundary of these two forms of solidarity. With reference to recent normative work on solidarity, I discuss norms of deference, voice, and accountability that should inform cancer screening debates.

The normative dimension of health insurance coverage: Women's views from Israel and Germany.

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Background: NIPT is available since 2012 in Germany and Israel, two countries that in certain respects represent opposing poles of professional cultures, regulations and policies regarding reproductive medicine. In both countries, there is currently a debate whether NIPT should be covered by the statutory health insurance. It is unclear how health insurance coverage might change the practice of prenatal testing. In light of the emergence of social and biomedical research around NIPT, we might regard this as a timely case through which to consider the nature of routinisation in health care. Health insurance coverage can transfer a normative dimension on three levels: (i) the guarantee of insurance coverage will attest a medical *necessity* to the emerging social practice of prenatal diagnosis; (ii) NIPT will be perceived as a *bonum* which is financed by the community as an expression of solidarity; (iii) it is part of a medical standard of care and women will become responsible for their *rejection*.

Work done: We conducted 80 semi-structured, qualitative interviews with woman who underwent, or refused, NIPT in Israel and Germany. Open-ended questions were used to explore

women's views on the normative dimensions of potential health insurance coverage, and how this might change their attitude towards using NIPT. Interviews were audio-taped, transcribed and analysed using a method of constant comparison.
Results: Both German and Israeli woman raised concerns about the issues of inequality in access, routinisation and the discriminating message sent by the test. In both countries, women consider prospective health insurance coverage of prenatal tests as a qualitative indication that this test is good for them. It takes away one more worry during pregnancy. In both countries, women expect the uptake of NIPT to increase if covered by health insurance.
While the general reasoning was similar, we found differences in justifications and the anticipated changes in testing-practice if NIPT were covered by the health insurance: While German women would not change their minds, *because* they would not act upon the information, some Israeli women would consider choosing NIPT, *although* they would not act upon the information.
Discussion: Health care providers have a strong influence on women's decisions. It is suggested that they should be careful when counselling for or against a test or procedure. Our study hints that health insurance coverage has a similar strong normative dimension which women implicitly understand as a positive qualitative indication for a test. The differences in expected changes of testing practice in Germany and Israel after health insurance coverage might be explained by a stronger implantation of genetic testing in Israel. In an ethical evaluation of the conditions of insurance coverage of NIPT, we need to anticipate that the application of tests according to the guidelines will lead to an escalation in the routinisation of genetic testing.

Ethics of pursuing targets in public health: the case of voluntary medical male circumcision programs in Western Kenya
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Originating from commercial manufacturing, the use of targets has become commonplace in public health policy and practice worldwide. Although its definition remains contested and its functions are diverse, a target is (roughly) a future desired outcome set in advance to structure an organization's activities, evaluate and monitor progress, and motivate individual agents (Locke and Latham 1990). The use of targets is generally regarded as beneficial, even indispensable, for health improvement initiatives, though some reservations have surfaced, particularly concerning health system reform (Bevan and Hood, 2006). The ethical challenges that can arise in the pursuit of health targets has received scant attention in bioethics.

We focus here on the use of targets in voluntary medical male circumcision (VMMC) programs to prevent HIV. Randomized controlled trials have indicated that male circumcision significantly reduces risk of female-to-male HIV transmission. VMMC initiatives in high HIV incidence/low circumcision prevalence countries (mainly in sub-Saharan Africa) utilize national, regional and program targets to increase numbers of circumcised adult and young males. Spearheaded by United Nations Program on HIV/AIDS and the United States President's Emergency Plan for AIDS Relief, well over 15 million circumcisions were performed in 14 countries in east and southern Africa between 2007 and 2017. Among those countries, Kenya is considered a 'success story', with over 1.6 million males have been circumcised; in 2017, 60% of the circumcisions performed were among 10-14 year olds.
To look more closely at the Kenyan story, our research team conducted empirical fieldwork on the implementation of VMMC programs in western Kenya. From March 2017 through April

2018, we carried out in-depth interviews with 29 VMMC stakeholders, including VMMC "mobilizers", HIV counselors, clinical providers, schoolteachers, and VMMC policy professionals. Additionally, we undertook observation sessions at 14 VMMC clinics, and observed mobilization activities at 13 community venues including, two schools, four public marketplaces, two fishing villages, and five inland villages. We found that the use of circumcision targets, along with the availability of male youth only during short periods ("VMMC seasonality"), resulted in overburdening of clinic resources and staff, long waits for care, coercive and deceptive mobilization practices, peer pressure, circumcision of children under the approved age of 10 years, and deviations from the standard of care.
We learned that the pursuit of VMMC targets can lead to ethically problematic consequences. To some extent, the public health success of Kenya's VMMC programs may be predicated on the sacrifice of other values, such as voluntary consent and patient safety. On the other hand, the use of targets in VMMC programs is unlikely to disappear, and their use can be justified generally in terms of number of HIV infections averted. How should the potential harms of targets be minimized? Should targets be made less ambitious, reducing the potential for coercion and other negative effects but possibly also decreasing numbers of those protected from HIV transmission in the process?

Considering AI/Machine Learning and Intellectual Resource Allocation

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Several years ago at a National Science Foundation-sponsored conference on nanotechnology, enhancement and ethics, biomedical engineers from two multinational corporations gave presentations about issues pertaining to equipping combat personnel with interfaced and/or implanted biotechnology systems. These modifications would create more efficient fighters, less susceptible to injury, with diminished nutritional needs and enhanced recuperative abilities. Each presenter posited that scientific understanding of human biology was such that the only obstacles to making a warrior's body completely self-sufficient — even to the point of the self-repair of traumatic combat injury — were simply unsolved engineering problems. The questionable veracity of such an extravagant claim aside, there was also a noticeable absence of any consideration of the ethics of utilizing such systems.
Their assessments of engineering as the nexus of what is often called "our biotechnological future" (Hyde & Herrick 2013) is a perspective they no doubt share with many transhumanists, whose arguments about the inevitability of technology-based (or even technology-driven) human evolution seem tantamount to quasi-religious. But biomedical engineers and transhumanists are hardly the only members of the intelligentsia for whom technology can displace more mundane, and immediate, matters of concern to the human species. One need to look no further than the debates concerning the moral status of artificial intelligence (AI), synthetic embryos, and the like.
This paper argues that the tremendous advances at the locus of computer science, AI and biomedical engineering can inspire a deference to engineering as an inherently superior problem-solving tool to the devaluation of other disciplines (e.g., humanities and social sciences). Similarly, the obverse — problems, especially ethical ones, that do not easily submit to engineering solutions, and therefore are given less than their due — is also a risk that deserves careful scrutiny. (Cf. the famous "trolley problem" thought experiment as it is currently applied to autonomous vehicles.)
Questions concerning the human species' duty to life forms or intelligences we create are by no means trivial. Our narrative traditions abound with cautionary tales on this matter, from the

golem in Jewish religious tradition to Pinocchio to Frankenstein's monster. It is nevertheless worthy of consideration whether the intellectual resources devoted to the moral status of AI — and which therefore are applied on behalf of AI — might be a more substantial benefit to humanity if applied for instance to less exotic conundrums such as the putative crisis of refugees currently in "internment camps" at the southern border of the United States. One wonders how they or migrants fleeing North Africa across the Mediterranean might respond to questions about the inherent rights of an engineering-based "life form." Add to this the growing body of research that teaches us that AI, far from making neutral or unbiased choices, can exhibit the same biases as their human progenitors.
Despite the promise that bioengineering and machine-learning systems offer to benefit humanity, the outsized faith that some have in them invite the suspicion that they may become the default from which any solutions of merit must derive.

Cognitive enhancement defined as a function of identity
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Medicine has the ability to restructure and shift human normative functioning with the development of enhancement technology. These interventions are classically developed for individuals with brain disorders or disabilities for therapeutic purposes, and subsequently applied to typically functioning individuals as enhancement. The definition of therapy versus enhancement has been the focus of debate but has yet to be discussed from the perspective of the people that have cognitive disability.
We conducted a survey of people with Down syndrome and their families, a group that has become an archetypal subject of normative functioning discussions as a result of prenatal diagnosis and preimplantation genetic diagnosis technology. Our results show an interesting trend. Of the 450 parents that responded to our survey, 92% of parents strongly agreed that they would give their child with Down syndrome a drug to prevent blood cancer. In contrast, only 59% strongly agreed they would give their child a drug to make them more intelligent and only 35% strongly agreed that they would give their child a drug so that they no longer had Down syndrome. Of the 51 people with Down syndrome that responded, 73% wished they could learn faster and 25% wished they did not have Down syndrome. These responses did not correlate with a calculated functional score of the person with Down syndrome. In general, individuals were more strongly inclined to intervene with diagnoses that are traditionally labeled as illness, versus diagnoses that are traditionally labeled as disability. Qualitative questions reveal that disability diagnoses are more closely linked to identity, and therefore were less perceived as requiring treatment.
From the perspective of the Down syndrome community, giving a cognitive medication to someone with a cognitive disability could be an unnecessary treatment and be considered enhancement. The definition of human enhancement may rely less on deviation from normal human functioning, and more on the relationship between the condition and identity.

The primacy of human being and the ethics of non-beneficial research
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Almost all international guidelines for biomedical research stipulate that the interests of the subject should always prevail over the sole interest of society or science. This principle of the

primacy of human being (PP) is considered to be the cornerstone of research ethics. However, it is unclear how it may be reconciled with the conduct of non-beneficial research involving incompetent subjects, especially children. The aim of this paper is to provide an interpretation of the PP compatible with the ethical practice of non-beneficial pediatric research.
First, I will briefly discuss history and normative role of the PP in research ethics. Second, I will argue that main justifications for non-beneficial pediatric research – namely, the "moral education argument" (Bartholome 1976,1977; Ackerman 1979,1980; Gaylin 1982; Redmon 1986); the "better overall life" argument (Wendler 2010,2012); and the "improvement of pediatric medicine" argument (Litton 2008, 2012) – rest on an assumption that a research project respects the PP when it promotes some of the subject's interests and threatens others, "but the ones promoted are superior in some relevant way to those that are impaired, so the result is a net gain for [the subject] on the whole" (Feinberg 1987:39). I will provide reasons for rejecting all these arguments and the underlying interpretation of the PP. Referring to Feinberg-London's account of basic and ulterior/personal interests, and "the secure child standard" developed by Shah (2013), I will claim that – in the context of non-beneficial pediatric research – the PP should be interpreted as requiring protection of the minor subject's basic interests against more than slight and temporary negative impact.
The proposed interpretation of the PP provides a theoretical support for a non-comparative approach to minimal risk standard, similar to the one adopted by the CoE Additional Protocol to the Oviedo Convention concerning Biomedical Research (2005).

Unraveling the interplay of mental illness and treatment decision making: Implications for clinical ethics

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With increasing frequency, assuring patients' informed consent for treatment is complicated by the interplay between mental health and health care decision-making. Patients requiring medical care may have concurrent mental illness that impacts their capacity to make decisions in their own best interest. Patients may arrive with prior or current psychiatric diagnoses ranging from anxiety, depression, or substance abuse through dissociative disorders, such Post-traumatic Stress Disorder (PTSD), Conversion Disorders, or thought disorders, such as Schizophrenia. Too often, clinicians are unprepared to recognize the nature of the psychopathology they encounter or gauge its impact on decision making capacity. These realities challenge clinicians in fulfilling their ethical and legal obligations for informed consent for medical treatment. Likewise, clinical ethics consultants may be uncertain about how to adjudicate these conflicts within the consultation process.
Commonly accepted criteria for decision making capacity in adults include: 1) ability to understand information relevant to the decision, including consequences of treatment and non-treatment, 2) ability to reason and deliberate about their medical circumstance in accordance with their values and preferences, and 3) ability to effectively express their choice[1]. This interactive session will focus on the interplay between patients' previously or newly diagnosed mental illness and their capacity to make treatment decisions. For the purposes of this discussion we will focus on three relevant mental illnesses commonly encountered in clinical practice. Paradigm cases will be described and discussed to illuminate the impact of mental illness on medical decision making relative to the nature and intensity of psychopathology and the significance of health consequences. Three elements should be considered: 1) the severity and relevance of mental illness to the specific treatment decision, 2) the complexity of the clinical circumstance and the decision that needs to be made, and 3) the likely consequences of

treatment or non-treatment, including the degree of certainty in treatment effect and the gravity of potential outcomes.
Participants will leave with an appreciation for how classes of psychiatric disorder may differentially compromise patients' capacity and with practical guidelines for clinical assessment, including key questions to guide clinicians and clinical ethicists in determining when patients' psychopathology precludes their making reasoned medical decisions. Related topics may include: aligning capacity criteria based on context and significance of medical decision, the role of justified paternalism, and capacity assessment in clinical practice vs. legal competence. When confronted with ethically ambiguous cases, guidance for clinicians and clinical ethics consultants to address their moral uncertainty and distress will be offered.

[1] Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. N Engl J Med 1988;319:1635-8. [Erratum, N Engl J Med 1989;320:748.)

What does autonomy mean in a clinical setting?
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In the bioethical discourse *„patient-empowerment"*and the *„informed patient"* play an increasing role. In most of the research both seem to benefit the decision-making process in a clinical setting and have a positive influence on the doctor-patient relationship. Informed patients know what is happening to them and understand consequences and benefits of therapies and medical methods. Based on this knowledge they decide autonomously and are the favoured counterpart for physicians.
However, the idea of autonomy is not just defined on the patient's side, it comes down to physicians too. Many questions may occur: How can I treat a patient as an autonomous person? And how do I know what autonomy means in a clinical setting? These questions are relevant because they show that the classic doctor-patient relationship is an asymmetric one.
So, does this asymmetry inevitably limit the patient's autonomy? Can new ideas of empowerment and information adjust the asymmetry?
The presentation will examine these questions in the light of different approaches to autonomy. It will try to translate well-established philosophical ideas of autonomy into a medical context. It will show that different approaches to autonomy can provoke variable outcomes in a clinical setting.

Digital Anthropology - Robotics and Artificial Intelligence in Medical Practice
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This presentation will start with a short overview about the development of robots for medical care that are expected to come into practice soon. Robots may deployed in various ways: logistics and transport services; cleaning assistance (e.g. if there is a strict quarantine); monitoring patients as an instrument of *telepresence;* they may assist in nursery care and application of medical interventions, e.g. in the surgical theatre; and, of course, there will be a role for emotional robots that are already in use and may be used more intensively in the future to socialize with people. Moreover, *intelligent robots* that may act as an instrument to support daily life of patients may be controlled by brain-computer interfaces. Examples of all these fields of application will be presented.

In a second step a short reflection will follow focusing on artificial intelligence, e.g. in conjunction with robot technique. Such applications have proved to be effective in pathology, dermatology, psychiatry, radiology and oncology.
In the third section I am going to discuss the concept of autonomy. An important distinction is to be made, i.e. the idea of technical autonomy versus personal autonomy. The discrimination between both ideas of autonomy is of particular relevance when ethical problems arise.
In the end I will present some of these ethical challenges associated with the application of robots in medical care. In particular I will focus on i: the relation of the idea of responsibility and the concept of personal autonomy; ii: the protection of private sphere and the right of informational self-determination if artificial intelligence is used; iii: the risk of losing emotional relation and reduced communicative practices if robots are used in nursery care and medical practice. Moreover, iiii: the robot technology may have impact on safety and liability in medical practice, as well as the concept of informed consent. And after all, the introduction of new technologies may increase inequalities in medical care if available only for the happy few who can afford high quality care.

Physicians´ intricate prerogative - Medical indication and medical practice
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The concept of *medical indication* constitutes a cornerstone of medical practice. Any medical intervention has to be based on a medical indication. Yet, it would be a misunderstanding to reduce the concept to medical efficacy. Rather, the concept encompasses an element of evaluation. Hence, it is not surprising that it is associated with ethical challenges. In a way the concept entails a hidden agenda: who has the power in medicine?
Perceptions about appropriate medical acts and interventions may differ: between patients and physicians; between one physician and another. What are the values physicians bear on when placing an indication?
The concept of medical indication may be seen as an evaluative link between diagnosis and treatment. 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 judgements, 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 in other clinical areas. Another relevant issue is that of overdiagnosing that prompt medical interventions despite an obligation to act seems questionable.
In this paper it is argued that the concept is a necessary element of medical practice. The philosophy behind refers to Plato´s idea*: the good is common to all*. Otherwise medicine would give up its trait being a social and solidarity-based enterprise.
Conflicts may arise if patients want treatments not held to be warranted. In case costs are covered by public insurances that may touch issues of fair allocation of resources. Even more important, treatment without given medical indication will destroy the very idea of medical practice. What is at stake is the concept of medicine: being a menu from which patients/ persons choose treatments or an activity based on an idea of the nature of man.
The right to place an indication is background of the particular role model physicians have in societies, which is brought to light e.g. by the obligation to be registered in medical councils or

chambers, by extensive duties to document their acts a.s.f. Moreover, it constitutes a duty to disclose indication policies, e.g. with respect to end-of-life treatments, organ transplantation and others more.

Medical tourism – Palestinian / Israeli infertility treatments

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"Medical tourism" occurs when people travel abroad in order to seek medical treatments that is not available in their home-countries. Usually, patients seek sophisticated and expensive care not available at home; but sometimes patients try to avoid regulation, for example, getting organ transplantation in manners that are illegal where they live.
Israel's advanced medical services attract medical tourism from diverse countries (30000 medical tourist per annuum). Some of these "tourists" seek infertility treatments, an area in which Israeli medicine is highly reputed. However, despite free and high-quality infertility treatments available to all Israeli citizens, there is a significant group of Israeli Arabs (i.e. Palestinians who are Israeli citizens) who travel to the Palestinian authority and pay thousands of Euros for private infertility care.
Some such patients seek to avoid regulation: sex selection, implantation of twins and treatments-on-demand. Some seem to prefer private and less regulated medicine, perhaps because their consumer power dominates over their patient position. Some patients bear diagnoses without any chance of fertility (e.g. azoospermia) and they seem to be lured by promises of cure.
In this talk, we will present this unique phenomenon, exploring its possible reasons and the ethical problems it poses to the gynecologist who is responsible for the care of patients who seek infertility treatments "abroad", which is few hours driving away from home.

Promoting structural justice through mobile health technologies? A global review and ethical evaluation of mobile apps targeting Violence against Women

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Violence against women (VAW) is a multi-layered and wide-ranging global health concern that requires effective and responsible intervention strategies on individual, societal and structural levels. Furthermore, the crucial role of primary prevention for global health interventions in general, and anti-VAW responses in particular, has been repeatedly emphasized. For this, it is essential to address and alter underlying structural causes of VAW (UN 2012), such as the concept of female inferiority.
One relatively new intervention strategy against VAW lies in the use of mobile technologies, such as mobile apps. Apps targeting VAW are currently being developed and deployed in great numbers. The proclaimed common aim of these apps is to provide (potential) VAW victims, bystanders and/or health workers with different anti-VAW strategies. In our previous work, we presented first results of an anti-VAW app review in India with regards to epistemic injustice. In this paper, we expand the systematic app review to the global scale, including more than 170 apps. Furthermore, we then evaluate anti-VAW apps through the lens of structural [in]justice (Young 2011).
In our paper, we first present the methods and results of our systematic global app review and discuss a selection of exemplary apps. Building on our findings, we identify trends of main app

categories (identified via main app function), of app category distribution in a global context, as well as target group distribution.
As second step, we discuss our normative framing of apps in the area of VAW on the basis of Iris Marion Young's concept of structural injustice and shared responsibility. Young's theory captures how social structures routinely and predictably produce structural injustice in constraining some people's options *unfairly*. Further, Young places special emphasis on every individual's shared responsibility in overcoming structural injustice. We argue that this theory represents a useful tool to evaluate strategies against VAW, which in itself presents a manifestation of structural injustice. Therefore, we critically assess if and to what extent anti-VAW apps address structural root causes and contexts that lead to VAW as phenomenon of structural injustice. Thus, on the basis of Young's theory, anti-VAW strategies can be assessed with regards to their potential function as lever in long-term, primary prevention. In our systematic assessment of anti-VAW apps, we could identify three shortcomings of said apps with regards to the structural nature of VAW. Firstly, too few apps shed light on the structural causes of VAW. Secondly, the analyzed apps insufficiently included non-victims as target groups and herein failed to discharge shared responsibility. Thirdly, mentioned shortcomings were most pronounced in areas with higher to highest rates of VAW.

Our paper is a preparatory step for further in-depth research and critical discussion on the chances and challenges of mobile health approaches to the global health concern of VAW. Furthermore, this work elucidates the need to assess health responses to VAW through the lens of structural injustice. For no health intervention is complete without prevention (WHO 2013) and promoting structural *justice* presents an essential lever in the urgently necessary long-term prevention of VAW. (word count: 500)

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Should patients with cognitive Impairment be involved in advance care planning?

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Respecting patient autonomy is challenged when the patient is no longer able to communicate preferences. However, the patient may still influence decision-making through advance care planning (ACP). ACP is a process of communication letting patients share their preferences and values for future medical care. Questions remain as to whether ACP is for all patients interested in discussing their preferences and values with health care personnel. Should cognitive impairment disqualify patients from relaying important information relevant to decision-making at end of life? This is a pertinent question because these patients are excluded from ACP definitions and to a little extent part of ACP studies.

Centre for Medical Ethics at the University of Oslo carried out an ACP research project that included a cluster randomized clinical trial. The background for the project was research from Norwegian nursing homes indicating little patient involvement in such conversations – despite several indicating a wish for being part of discussions, little use of ACP, next of kin getting too much responsibility and health care personnel wanting more competence in doing conversations. Consequently, the research project aimed at involving nursing home patients more in discussions about end of life. We, the researchers, trained and supervised health care personnel in doing ACP. Training and implementation support emphasized involvement of as many patients as possible in ACP. This included patients with cognitive impairment, and we encouraged next of kin to support patients during ACP.
Results were positive, suggesting the above questions may be answered "nope". Chart reviews before and after the one-year intervention period, indicated patients more involved in ACP – including patients with cognitive impairment. Observations of ACP found patients with cognitive impairment as active participants of ACP able to communicate relevant information. During qualitative interviews, health care personnel and next of kin claimed ACP had been patient-focused. Nevertheless, involving patients with cognitive impairment in ACP is challenging because they may lack focus, interest and competence in discussing end-of-life issues. Furthermore, almost two thirds of patients did not participate in ACP in the intervention group, which may suggest that many nursing home patients are not capable of participating meaningfully in ACP. ACP should thus be initiated at an earlier stage than after nursing home admittance.

The response of the profession of pharmacy to legalized assisted suicide and euthanasia
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s If AS/E is legalized, pharmacists become directly and inevitably involved; for even if physicians have to issue the prescription, pharmacists are responsible for filling the prescription. The ethical assessment of this involvement is complicated by a variety of factors including: (1) There is on-going societal debate whether AS/E is at all a form of health care proper that should be put on the shoulders of health care professionals. (2) Pharmacists are often – specifically in the case of AS in the USA - the last health care provider in the chain leading to patients obtaining the lethal drugs. (3) And yet pharmacists typically have no control over the decision-making process. Finally, (4) pharmacists have not been given the same special role and status in the law that physicians have been given when assisting in a person's suicide. We review the diverse ways in which different professional associations in pharmacy have responded to the ongoing process towards legalization of AS/E and the increasing incidence of AS/E in jurisdictions where AS/E has been legalized.

Trust, death, and suspicious circumstances - a 21st century Jekyll & Hyde case?
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In 2015, former nurse Nils H. received a life sentence in Germany for killing six of his patients. During the court case there was further cause for suspicion and the police set up a special task force. Its investigations have led to a return to court for Nils H. He was accused of committing 97 additional cases of murder at two different hospitals in the North of Germany in his function as a male nurse. During his work as a nurse, he allegedly injected severely ill patients with

various medications to trigger life-threatening cardiac dysrhythmia, in order then to attempt reanimation and prove himself to his colleagues and superiors.
It could be the most comprehensive serial killing ever in post-War Germany. And committed, of all people, by a nurse. Against patients who were helplessly dependent and who had placed their trust in the institution hospital. Employees in areas inviting a high level of trust from the population do, from time to time, make newspaper headlines for causing precisely the type of crisis they themselves are there to prevent (e.g. a fireman who starts a fire himself in order then to put it out with his colleagues). But in this case the sheer number of hospital deaths presumed to have been caused by one man defies belief.
The case of Nils H. has sparked many questions: How can such behaviour remain undiscovered for such a long time? And in an area of the hospital in which many people from different disciplines work hand in hand? Did it go unnoticed because the perpetrator had two faces, a Jekyll & Hyde character who kept his dark side well hidden? And if there was any suspicion, why did this not lead to rapid discovery of the crimes and prevention of their continuation? Cases from other areas (e.g. staff corruption, staff alcohol or drug addictions…) have shown that many factors can obstruct consistent steps from being taken within an organisation. But when people entrusted to an institution's care (in this case the patients) are in great danger, it is crucial from an ethical perspective that immediate measures are taken in order to avoid any further danger. Employees and their superiors have not only an ethical, but also a legal responsibility, as was shown by the subsequent prosecution of six members of staff (physicians and senior nurses) for "death through negligence" when they were allegedly not decisive enough in their actions after hearing about staff suspicions.
The (organisational) ethical questions to be clarified here are: What would the wording of a list of measures informing hospital staff and those in positions of authority how to behave in suspicious circumstances have to be? What exactly should be done if a member of staff approaches the ethics committee with such suspicious circumstances? And can the ethical evaluation of such a case be helped in any way by taking a look at the "Strange Case of Dr. Jekyll & Mr. Hyde"?
This talk will provide a short summary of the events above and examine the ethically appropriate way to deal with suspicious circumstances. (Organisational) ethical aspects will be addressed, and a link made to R.L. Stevenson's "Strange Case of Dr. Jekyll & Mr. Hyde".

Medicine 4.0 – Development of a criteria matrix for the ethical assessment of health-related apps

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Digital technologies are now permeating almost all areas of life, creating a variety of data. These include wearables, sensors and trackers in healthcare and beyond. The ability to continuously and flexibly collect health-related data and make them available to the user can, for example, strengthen patient autonomy, but there are also risks in terms of privacy, data security as well as in terms of the validity and contextualisation of the interpreted results.
The potential benefits and risks of collecting sensitive data in this way should be ethically weighed in a new digitised context of different actors and interactions, including technology developers, healthcare and insurance structures. To be able to elaborate an adequate scientific analysis of these changes and provide responsible ethical assessments, it is necessary to achieve a multi-faceted analysis, which in this project is based on interdisciplinary cooperation.
In the context of our project funded by the German Federal Ministry of Health, "Medicine 4.0 - The ethical basis of digitalisation in health care", a cooperation between the University of

Bayreuth and the University of Munich (LMU), we analyse digital technologies in health care by combining empirical research and normative analysis. We focus on two specific areas - medical and health-related apps as well as telemedicine with a special focus on telemonitoring. In this iterative interdisciplinary approach, we link social science research on the ethically relevant effects of these technologies, including on the doctor-patient relationship, the relationship between self-responsibility and solidarity and the autonomy of the individual, with the normative premises of a principle-oriented ethical approach, to be able to create an evaluation matrix.
Based on previous work on the evaluation of eHealth applications in general (see in particular Marckmann, G (2016)), this matrix intends to integrate evaluation criteria from the areas of medical and technology ethics. The focus is on the coherent development of this approach in the light of recent insights in the field of health-related apps.
Our contribution in Oslo aims to address a specific aspect of this research. Based on exemplary effects of mobile applications, we outline possible shifts in responsibility and their consequences for patients and other users of apps and their relationships with stakeholders in health care. The basis for this is provided by a qualitative empirical (interview) study currently being carried out, which highlights various aspects of the stakeholder's perspectives on the effects of the technology and analyses these regarding ethically relevant issues. By analysing the different perspectives of those involved, ethical areas of tension can be identified. In combination with the evaluation matrix, this research should form the basis of overarching recommendations on the development and use of health-related apps.

The concept of moral injury: a critique
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In an era of wars, terrorism, financial crises, and environmental emergencies, psychological questions regarding trauma and resilience have taken on a new sense of urgency. The established way of thinking about trauma, enshrined in the PTSD diagnosis, is facing growing resistance from those who argue that this psychiatric perspective underestimates the resilience of human beings. Others claim that the diagnosis has drained the trauma concept of its moral and existential meaning. “Posttraumatic stress disorder,” these critics point out, originally addressed the rage, shame, guilt, and depression experienced by many American veterans returning from Vietnam. Today, however, PTSD has become fully incorporated into a reductionistic diagnostic apparatus of quantifiable symptoms and measurable improvements. In response to this medicalization of trauma, “moral injury” has emerged as a counter-concept to PTSD, seeking to reclaim the earlier understanding of traumatization as a *moral* form of suffering. The concept captures the notion of being haunted by one’s past, and the sense of having been diminished by the horrible things one has seen or done or suffered. In this paper, we explore the theoretical foundations of “moral injury.” We argue that the psychological mechanism in moral injury is too narrowly defined, as cognitive dissonance between moral beliefs and action. The moral psychology of violence cannot be understood in strictly cognitive terms. Dissonance is not simply an internal tension between beliefs and action, but reflects the many forms of discord in one’s complex relations with other individuals and groups that make up the emotional responses to violence.

Sharing body material. The case of bone marrow transplantation between siblings
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The presentation will be based on a philosophical and a qualitative empirical study on bone marrow transplantation (BMT) between siblings who were children at the time of transplantation.[1] Central philosophical themes were discussed in the first study. 17 families which have experienced a bone marrow transplantation practice were interviewed in the empirical study. In this study, family group interviews and interviews with the family members (82 interviews) were conducted in order to find out how family dynamics have developed and how individual members feel about themselves, their roles and the family relationships during the time of illness and the time thereafter. The illness of the one child and the transplantation of stem cells from the healthy sibling sets free a family dynamic that provokes, among many different aspects, to question the *family as a body*, the bodily aspects of the transplantation practice, and the role of the child's body.
One of the questions in the interviews included also the theme of the body material. It was asked whether it mattered in a particular way that the receiver of the stem cells had been given body material of his or her sibling. Some family members felt that because of the new bodily relation a particular *bond* between the siblings is manifested. In my presentation, I will discuss different dimensions how the transplanted body material and how the practice of *sharing a body* can be regarded: (1) The idea of the transplant as a *gift of life* and a new birth; (2) the fear of being used as *spare part depot*; (3) sharing the *same thing* and the bodily bond; (4) the body substance being from the family, i.e. the child, and not from an anonymous stranger. Detecting and discussing these different dimensions of the body will deepen the philosophical and social understanding of transplantation practices, pediatric concerns, and familial relationships.

[1] The empirical study had been mainly conducted by Madeleine Herzog and Dr. Martina Jürgensen; I was Co-PI with Professor Christoph Rehmann-Sutter. This study was linked to an earlier philosophical study by Christina Schües. Funding was provided the German Ministry of Education and Science (BMBF) and Fritz Thyssen Foundation.

Are we designing now or what?[1]

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Many people oppose the creation of so-called designer babies, even though it is not evident to argue why – if at all – this is morally wrong. Yet, not only the idea of 'designing' offspring is ethically controversial, also the popular concept of 'designer baby' is contested. It happens to be particularly complex to arrive at a conception of what it actually means to 'design' children. There is relative consensus about the idea that the creation of designer babies involves interventions in order to influence the traits of future offspring, but this is vague, and it can be rightly asked which interventions and which traits one is talking about. Germline gene editing seems to count as the paradigmatic way to generate designer offspring, and, if taken literally, one does not *design* offspring if one *selects* embryos via e.g. pre-implantation genetic screening. Should we install a morally relevant distinction between 'designer babies' and 'selected babies' even if the preferred outcome is the same? And what about the purpose of these interventions? Much of the moral controversy surely has to do with the non-medical, but even if one limits the discussion to this subset, it is also appropriate to distinguish non-medical interventions aimed at enhancement from non-disease related interventions that are aimed at feature selection, but not at enhancement. Furthermore, if the presumed normative impetus against the designing of offspring comes from choosing preferred non-disease related traits, why then is there not a similar moral opposition against the widespread preference for a genetically related child, even in situations in which this preference comes at a cost in terms of societal investments or health

risks for the future child? A desire for a genetically related child is also a specific wish about the future child's characteristics, all the more because many people want a genetically related child because they value parent-child resemblance, which is actually a wish for a child who shares some of the parents' (preferred) traits. This is similar to future parents who choose a gamete donor in function of his/her characteristics, though in this context this is often disapproved as a 'designer method'. During this presentation, these questions will be addressed so as to problematize the notion of 'designer offspring' and explore the moral boundaries between designing and not designing.

[1] The choice for this title was inspired by Greta Christina's blog post 'Are we having sex now or what?'

Descartes' Ghost at the End-of-Life: Phenomenology and the permissibility of assisted suicide in depression

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This paper employs phenomenological-philosophy to argue that some cases of intractable depression, it may be permissible to approve a depressed person's WTHD request. Even though depression and cessation of life is a highly contentious issue, by continuing to situate the debate within ethical, juridical, or psychiatric frameworks, we learn nothing of *what it is like* to suffer with depression. Phenomenologically speaking, experiences of depression are often marked by changes to the entire way in which a person finds herself in the world. Depression patients commonly report experiencing more than symptoms such as low mood or lack of meaning in life. Many people experience affective disturbances: estrangement from the world, disconnection from others, alienation, loss of practical possibilities, and/or overwhelming feeling of "not feeling." Unsurprisingly, then, failure to take lived-experience seriously inhibits our ability to understand why depression might compel someone to request a WTHD.
The phenomenological perspective has two contributions on this issue: first, it views suffering in depression as a serious source of evidence to argue that certain ways of being-in-the-world may be intolerable. Second, it exposes how somatic medicine and psychiatry have failed to step out from the shadow of dualist ontology. Absolutists, who outright reject the possibility approving WTHDs for depression use a qualitative hierarchy of suffering to distinguish physical suffering from psychic suffering. Why? Somatic suffering is generally amenable to empirical observation while psychic suffering is significantly less conspicuous in third-person observations. This view of suffering, however, draws explicitly from the mind-body distinction, the legacy of which medicine has attempted to distance itself from during the last century.
Similarly, disagreements over WTHD are often confined to definition of concepts, particularly those associated with decision making capacity: autonomy, agency, competence, and so forth. The amount of attention accorded to decision making and competence is attributable to assumptions that requesting a WTHD is inherently irrational; expressing a wish to die itself serves as evidence of incompetence. Yet, if we turn attention to lived-experience, we can call into question whether decision making is typically an explicit exercise of rationality. Phenomenology offers a third way to understand what it is at stake when deliberating on the permissibility of WTHD made by patients with depression.

Physicians and retirement: why are retired persons often relegated to an "outlier" status in society?

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Background: No universal standards exist for medical retirement with few medical networks mandating retirement at a given age and most administrative bodies permitting licensure-competent physician activity from licensure through death. Should additional universal guidelines be established for medical retirement, for the protection of patients? This is done in the aviation industry that does not license pilots over age 65.
The word "retirement" derives from Middle French, to withdraw back. In medicine, the Hippocratic oath, has been interpreted to put limits on one's outside activities in order to" use treatment to help the sick according to my ability and judgment" (T.A. Kavanaugh, Hippocrates' Oath and Asclepius' Snake). Retirement loosens this oath as retirees seek other engagements in life be they, for example, sports, reading, or travel.
Methods: PubMed and Google Scholar sources were surveyed for ethical articles dealing with medical issues. In addition, the policies of the 50 US states, through their websites, were reviewed for retirement subjects including inactive licensure, charity work in retirement, and patient relationships after retirement.
Findings: The median retirement age (data, 2010-2014) in the US is 66.1 and from clinical activity 64.9. Retirement policies, when they exist, are found in the public but not the private sector. The U.S. states have never had mandatory retirement policies, although two European nations (Germany and the United Kingdom) with a mandatory retirement age in the past have abolished such policies. The urge toward mandatory retirement is discussed more commonly among specialties with procedural orientation (surgery, anesthesiology).
Nevertheless, the cognitive decline associated with age is no exception in medicine. In one series, the only variable associated with having a malpractice suit is length of time in practice. A minority of U.S. states have explicit policies regarding work during inactive licensure and others facilitate the use of physicians in retirement doing charity care.
Discussion: to what degree do physicians who continue to work despite cognitive decline harm the public? Should physicians be required to pass examination after a certain age to show persistent cognitive abilities? The American Medical Association advocates for a transition to full retirement by simplification of medical forms, decreased cases loads, and a narrowed focus of care as three ways to assist older physicians. How often is physician retirement affected by economic conditions? Alternatively, do psychological factors with a "need to work" determine time of ultimate retirement?
Conclusion: The American penchant for professional anti-age discrimination may not always considered in the best interests of patients. The modes of evaluating age-related decline, the need to transition to activities that typify the best traits of older generations and the logistics of such implementation need further study. While it may be prudent to limit surgical or anesthetic skills by age, even more prudent is it to provide avenues for creative thinking and teaching with older age. Licensing bodies, particularly, should facilitate the transition of physicians to less strenuous activities, limit patient caseloads, but allow for skills that facilitate self-image in the elderly including limited charity work.

Views and experiences of transcranial direct stimulation (tDCS) in children– findings from an interview study

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Introduction: Transcranial direct current stimulation (tDCS) is a brain stimulation technique offering an alternative or complementary treatment for various neurological disorders. Little is

known, however, about experiences of the participants undergoing tDCS treatments in clinical trials. Their views and understanding of this technique are an important contribution in the societal debate on ethical issues of tDCS, especially in pediatrics. This project aims to contribute to closing this gap by exploring the experiences of both healthy children undergoing tDCS and their parents/carers.
Methods: in-depth interviews study with children from a control group undertaking tDCS and their parents (n= 32)
Results: Interviewed children reported overall good experiences with the. They were able to see how their participation might help to develop treatment for children affected by neurological disorders. They could also see a potential of using tDCS in a non-medical setting. However, this could be an indicator of their limited understanding of neurological enhancement. Parents also presented a positive attitude towards tDCS, they saw it as a promising and safe alternative to medication in neuropsychological disorders. Nevertheless, their understanding of tDCS was rather poor. Even though many of them understood the techniques, they often did not see the link between the (current) lack of side effects and an absence of longitudinal studies. Even while many of the parents saw medication as a negative approach to treat ADHD, they were in favor of tDCS as a treatment. However, their views on developing a home device for tDCS were mixed. Also, unlike children, parents were cautious about using tDCS for non-medical/enhancement purposes.
Discussion: There is a need for more transparent information about the state of the art of tDCS, its function and what it actually might be able to offer. It is especially important in order to prevent unrealistic hopes and to make future patients and carers more aware of the potential side-effects and long-term effects of tDCS. This is vital in the sake of ensuring informed decision-making.

Is self-expression through typing (SETT) a valid method of meaningful communication for minimally verbal (MNV) autistics? A pilot (continued…)
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In the autistic spectrum disorders (ASD) non-speaking or minimally verbal (MNV) autistics represent the most challenging category as they are diagnosed as profoundly retarded. However, are MNV autistics incapable of intellectual cognition? Or are they intelligent, but 'just' incapable of verbal communication? The aim of this research is to demonstrate that self-expression through typing (SETT), learning to point autonomously at the alphabet to communicate, not only words, but also thoughts and ideas, is a valid method of communication for non-speaking and MNV autistics.
The importance of this research is that meaningful communication with SETT may become a useful channel to unveil the huge enigma posed by MNV autistics. Moreover, if SETT is validated as a universal intervention for MNV autistics, the diagnosis, prognosis and intervention policies toward MNV autistics would have to be reevaluated. Further, SETT could be learnt and circulated for the betterment of MNV or non-speaking autistic people, their families and caretakers; and become part of the regular curriculum in schools. In this paper we present challenges and first findings of this pilot.

Ascertaining child's "best interests" through direct-to-consumer genetic testing: what could possibly be wrong with that?
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Despite some early criticism for treating human genetic data as a special category of data and affording them special protection, many law and policy instruments have remained firm. They commonly contain significant reservations on the application of genetic testing on children, treating these interventions as impermissible, unless carried out for a direct (and immediate) health benefit of the respective child.
The increasing understanding of the human genome coupled with advances in technology is a fruitful soil for hopes, promises, and exaggerations. A hallmark of these advances and characteristics is direct-to-consumer genetic testing, which is commonly portrayed as "an empowerment tool" enabling the users to "take control" over one's health and even life choices. Moreover, it has been portrayed as the tool to help parents make "informed choices" regarding their children, their health, skill and talent management.
In addition to the obvious mismatch between the restrictive law and policy stand and the current practices of direct-to-consumer genetic testing companies, that raise questions of adequate protection of the rights of children, profound governance questions emerge. In this talk, I will scrutinize the practice of direct-to-consumer genetic testing from a child's perspective, and limitations of the current regulatory standards, and highlights ways forward.

Sensing mental health. The use(s) of sensor technologies in mental health care
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Sensor technologies (such as wearable devices, mobile sensors, bodily sensors and environmental sensors) represents a new form of potentially disruptive technology that could transform psychiatric practice. My aim in this presentation is to give an overview of ethical challenges that arise when sensor technologies are implemented and used in the context of psychiatric care. My main example in this regard is the use of sensors and see-through technology to continually monitor at-risk patients (e. g. suicidal patients). The ethical challenges that I focus on will have to do with privacy, informed consent, patient autonomy and more generally the morally harmful implications that such applications may have for the psychologically vulnerable. I then further ask whether the principle of caution should be applied in certain cases, to mitigate unforeseen consequences, and to restrict the technology from being misused (or perhaps in some cases even being implemented at all). Misuse or not, a precautionary approach may in any case be needed - if simply for no other reason than our current lack of knowledge of the potentially harmful effects.

Beyond moral status: the reification of the human embryo
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In the wake of in vitro fertilization in the 1970s, the human embryo almost overnight became a new sort of moral entity: one which could exist outside a woman's body. Since these possibilities were so new, there was little philosophical work to draw on. Mary Warnock's report on the ethics of embryo research and in vitro fertilization was a first philosophical attempt to shed some light on the issue of how human embryos in vitro could or should be treated. However, the moral status of the embryo remains a contested question. Public attitudes are still polarized: those who view life as starting at conception may repudiate any activity that involves

the destruction of an embryo. For these people, the embryo has full moral status. Those who endorse the creation, use and destruction of embryos for research and fertility treatment, face a more complex problem: to specify exactly what the moral status of the embryo is. Warnock argued that it has 'special' status and must not be treated 'frivolously'. But it remains an open question what such treatment entails, and whether the mass creation and destruction of embryos is not in itself a form of frivolous treatment. Since the early days of IVF and embryo research, new possibilities have emerged. The creation of parthenogenic and chimaeric embryos bring new challenges to the fore. The development of 'artificial gametes' likewise changes the assumptions surrounding the ways that embryos can be created. It seems that the moral status of the embryo has not fully been determined. This problem is more pressing in jurisdictions that permit embryo research. My paper will address the question of the morality of using human embryos in fertility treatment and research from a new perspective that has not yet been discussed in the literature. That is, in *using* human embryos, we may thereby reify them. The project will explore the question of what reification is, and how it differs from commodification or exploitation. Reification is a useful concept in the context of non-sentient entities specifically because it does not revolve around the need for scientific certainty about the properties that entity has (e.g. the capacity to feel pain, the capacity for consciousness, etc). Rather, it concerns the dispositions of those who are functioning as moral agents. I will establish whether reification of the human embryo is involved either in research or in fertility treatment. I will consider whether reification in these contexts is invariably morally wrong. And I will explore the possibility that certain forms of activity, e.g. scientific research, are necessarily reifying towards the subjects of that research. Finally, I will outline the ways in which regulation and legislation should respond to the reification of the human embryo.

Deciding on the use of biomarkers to estimate one's risk to develop Alzheimer's dementia: Applying the method of reflective equilibrium

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Identifying those at increased risk to develop Alzheimer's dementia by testing biomarkers has recently been a main focus of Alzheimer research. These biomarkers, measured via a lumbar puncture or a brain scan, are believed to reflect the process that is causing Alzheimer's dementia years before the occurrence of clinical symptoms. It is hoped that by intervening early in this biological process, dementia might be prevented or slowed down. Although this research strategy did not result in an effective intervention so far, Alzheimer biomarkers are increasingly applied in clinical practice to predict dementia.
This movement has sparked a widespread debate on its ethical desirability in general, even though the ethical desirability ultimately depends on the specific context in which biomarker testing is considered. In this paper, we offer an example of how one can decide on the use of Alzheimer biomarkers in a specific context by using the method of reflective equilibrium (RE). In the RE, considered moral judgements on the topic –gathered by us in a systematic literature review and interviews with medical experts-, relevant facts, ethical principles and background theories are weighed in light of consistency: the option that is supported by the most consistent and strongest argumentation will be the preferred alternative.
Imagine a 76-year-old woman who visits a memory clinic because she has memory troubles that are worse than the expected age-related decline. She is afraid that she will develop Alzheimer's dementia and end up in a nursing home. Should the physician offer her biomarker testing to estimate her risk to develop Alzheimer's dementia?

Considered moral judgements given in favor of biomarker testing are: 1) it will provide increased planning possibilities and 2) people should make this decision themselves, out of respect for autonomy. Relevant facts from the literature show, however, that the added value biomarkers for the prediction of dementia over a memory test, is very limited for people older than 75 years. Hence, biomarker results will not provide any new planning possibilities [1]. We will argue that as long as the results will not provide information that will foster free choice, biomarker testing cannot be supported by the ethical principle of autonomy [2]. Furthermore, being at increased risk may cause psychological stress in absence of a disease-modifying treatment.
Taking all elements in the RE in consideration, we conclude that Alzheimer biomarker testing should not be offered in this case because this option is supported by the strongest and most consistent arguments.

When the moral equation does not add up – on the phenomenon of moral residue
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An important challenge in moving from ethical theory to practice is accounting for the phenomenon of *moral residue* (MR). While ethical theories tend to assume that in every situation, there is some morally right thing to do, in practice, moral agents often encounter situations in which there is no morally good option available or in which, for a variety of other reasons, moral failures are unavoidable. The term *moral residue* refers to an agent's response to facing a moral requirement that remains binding despite being or having become impossible to fulfill. It is used to characterize an agent's distress experience of doubt, regret, remorse, guilt and shame that may emerge in the wake of a moral dilemma or other experiences of unavoidable moral failure. The negative and self-directed emotions arising from MR derive from the agent's being locked in a situation in which some moral failure cannot be avoided; the agent often has a sense of responsibility for this failure, despite the failure's being at least partly outside the control of the agent. Because the moral failure could not have been avoided, it will generally be inappropriate for others to blame the agent for it; however, at the same time, the agent's *self*-blame in such situations is common, and a lack of MR may even reflect poorly on the agent. People who experience MR need a way to understand and accept it so as to maintain their dignity while living with or through it.
In 1965 Bernard Williams started a debate on this phenomenon by claiming that ethical theories are unable to account for the phenomenon of MR. Since then, some, but not much attention has been paid to MR in moral philosophy and applied ethics. Most ethical theory seems to assume that MR can be nothing more than an irrational response, either because moral conflicts do not occur or because moral conflicts occur but can always be resolved without remainder. We believe that ethical theories are limited in what they can say regarding MR, and we think that narratives are more promising in this regard; they can offer audiences transformative experiences enabling them to understand and accept their own agency as the kind of moral agency that is vulnerable to the experience of MR. We thus propose to use a narrative approach to systematically explore MR, drawing on ancient Greek philosophy and drama. In this paper three different types of MR will be explored: MR due to normative ignorance, (aporia), MR caused by situations of double constraint (tragedy) and MR arising from situations of actual or perceived impairment of moral agency (comedy).

Two ways of belonging? Ritual circumcision of boys in liberal European democracies

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Opposition is building in Europe against ritual circumcision of boys, and a number of countries have debated outlawing the practice. Ritual circumcision of boys in European liberal democracies represents a challenging dilemma: Unlike in the US, there is no history for circumcising boys in Europe, and there is no tradition of acknowledging medical benefits (among healthy children) from the procedure. From a European medico-ethical perspective, the practice is perceived as harmful, and thus conflicting with the prevailing ethical principle governing all medical treatment of children: the child's best interest principle. In several European countries, you can circumcise your son if you are a Muslim or Jew, but you cannot do it without a ritual justification. From one perspective, it is pertinent to talk about unequal legal safeguards of children.
At the same time freedom of religion is recognized as a basic human right in Europe, and tolerance is considered a fundamental virtue among Europeans. Ethnic minorities and indigenous people are today met with respect and recognition of their distinct identities (for instance the Sami people in Norway). Jewish and Muslim religious leaders, however, have claimed that outlawing ritual circumcision represent a fundamental attack on their religion, identity, and way of life, in effect making it impossible to continue to be a practicing Muslim or a Jew in Europe.
In this paper, I will show how ritual circumcision of boys in Europe engage questions ranging from narrow debates in medical ethics to broad political debates on immigration and integration. Taking departure from Charles Taylor's writings on liberalism and communitarianism, I will discuss the issue of circumcision in the framework of different ways of belonging to a liberal state. The aim of my paper is to investigate whether a peaceful resolution of group and individual interests, in accordance with central principles of medical ethics, is possible in this case - or not.

The Devils in the DALY: Evaluating disease burden in the Global Burden of Disease study
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The Global Burden of Disease study quantifies disease burden via *disability-adjusted life years* (DALYs). It has, in recent years, become commonplace to regard the disability-adjusted life year primarily as a *descriptive* health metric. Our aim is to argue that the DALY remains largely *evaluative*. In this article, we identify numerous assumptions underlying the DALY and group them as descriptive, evaluative or undetermined. Our analysis focuses on the two most significant phases of the Global Burden of Disease publications from their beginning (1990–1996) to the most recent releases (2010–2016). We argue that the disability-adjusted life year remains largely evaluative rather than primarily descriptive.

Defining Premature Death
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Researchers in disciplines that study mortality—e.g. demography, epidemiology, and health economics—are often particularly concerned about premature mortality. Among other things, researchers of premature mortality identify targets for policy interventions, evaluate the

effectiveness of such interventions and monitor trends in population health. The claims of these researchers are therefore not inherently descriptive but value-laden with *prudential* assumptions about the times at which death is bad for its victim and *normative* assumptions about how life expectancy ought to be distributed.

Unfortunately, few have attempted to define "premature mortality" with this value-ladeness in mind. Currently, there is neither an established definition of premature mortality nor any consensus on which deaths we should count as premature. The measures most-often used to track this phenomenon have operational but not theoretical definitions (see Table 1). For example, many measures set arbitrary age-based thresholds (e.g. 75 years) under which all deaths are counted as premature. Other measures use specific causes of death (e.g. tobacco or lack of medical care) as proxies for whether the deaths in question were avoidable. But absent theoretical justification, there is no reason to think that any of these measures delineate premature deaths from other deaths. Furthermore, absent prudential and normative justifications, there is no reason to prevent these deaths rather than other deaths.

In this article, we explore two issues facing attempts to provide theoretical definitions of premature mortality in terms of age-based thresholds. First, such definitions are vulnerable to moral vagueness. For any plausible threshold there would be borderline cases, fuzzy boundaries and Sorites paradoxes. This, we argue, does not necessarily undermine the existence of premature mortality as a value-laden concept but imply that its "value elements" cannot be accounted for solely in terms of life-years. Second, the normative assumptions of such definitions are best explained by *lifespan sufficientarianism* (i.e. that there is a sufficient length to life that is enough for every person). This is problematic for two reasons: (i) because we cannot seem to fix such thresholds at any precise point given the moral vagueness alluded to above, and (ii) because our intuitions on where to fix such thresholds are contingent on our current mortality trends, which could change radically in the future. We conclude that premature mortality cannot be coherently defined in terms of age-based thresholds.

The Fragility of Patient-Trust

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A perspicuous understanding of the allocation of epistemic authority in the patient-provider relationship reveals that patient-trust in healthcare providers is *fragile*: it is more vulnerable to justified defeat than commonly supposed. I follow Baier (1986) and Jones (2012) in conceptualizing trust: when a patient trusts a provider with his health, he relies upon her *good will* to motivate her to exercise her *discretion* and *expertise* in caring for him, recognizing that his health is at *risk* and so distinctly *vulnerable* if the provider does not come through. This conception of patient-trust is supported both by traditional construals of the goals of medicine and by contemporary perceptions of healthcare providers (Hippocrates 1984; Galen 1997; Beitat 2015).

Patient-trust is *justified* or rational when the patient has *good reasons* to pursue a goal (health) that he cannot pursue without relying on others (the provider/providers), has *good reasons* to believe that the provider chosen is minimally qualified, and *lacks defeaters* for the belief that the provider will be *trustworthy*. Analogously to some views of testimony, trust in care-providers is here treated as default rational, but subject to on-going monitoring for defeaters (Fricker 2007, ch. 4).

There is significant asymmetry in the standard patient-provider relationship: qualified providers have *epistemic privilege* and institutional *authority* relative to patients. This asymmetry provides *prima facie* reasons to trust providers, and grounds the intuition that

patient-distrust of providers is typically *unreasonable*. Against this intuition, I argue the patient too has a kind of *epistemic privilege*. First, the patient has distinctive access to what it is like to subjectively experience his condition (Carel 2008). Second, the patient lives with his condition continuously, so has more data concerning it. Third, the patient is typically in a better position to understand what is all-things-considered best for him, including health objectives (Veatch 2009, 2012). The patient-provider relationship is thus characterized by two interacting types of epistemic privilege.
The patient's epistemic privilege provides him reasons to think his condition-testimony and preferences should be taken seriously. If these are consistently devalued or ignored, he acquires reason to doubt the provider is appropriately aware of important information about his condition or of what he construes as his best interests and so as endorsable goals of treatment. Reason to doubt whether the provider lacks these things *is* reason to doubt whether the provider *can* or *will* pull through concerning what the patient has entrusted her with, so is reason *not* to trust her. *Epistemic injustice* occurs when someone is wronged in their capacity as knower (Fricker 2007), typically by being ignored, devalued, or daftly misunderstood (Carel & Kidd 2014), while depersonalization involves experiencing oneself as a mere object in the perceptions of care-providers (Anderson 1981; Peloquin 1993; Carel 2008). Both epistemic injustice and depersonalization represent affronts to legitimate patient-epistemic-privilege, and so reasons not to trust. Epistemic injustice and depersonalization are intrinsically *possible* in the patient-provider relationship, are *encouraged* by provider-patient power-asymmetry, and are likely common in contemporary medicine, hence the warranted fragility of patient-trust.

Is suicide tourism a moral phenomenon?
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Unlike most of the (relatively few) countries which permit assisted suicide in their laws, Switzerland does not disallow this practice from non-residents either formally (like in Oregon, USA) or substantially (like in the Netherlands). Hence, in recent years there has been an increase in the number of people travelling to Switzerland from all over the world to receive aid in dying. In the literature, this phenomenon is referred to as "suicide tourism".
But is this phenomenon moral? Can it be justified on substantial grounds? It seems clear that whether countries from which people travel to Switzerland to receive assisted suicide should interfere, regulate and enforce policies pertaining to such a phenomenon depends on the moral and philosophical justifications for and against the phenomenon of suicide tourism. These should be distinguished from the justifications for and against assisted suicide.
The talk will present and discuss three arguments in support of suicide tourism and four arguments against this phenomenon. It will then evaluate these arguments and conclude that there are stronger and more convincing arguments in favor of suicide tourism. These arguments provide a *prima facie* justification for such a phenomenon.

Ethic of Nudging in Neonatology
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Background: The way choices are presented has an impact on decision-making and the intentional alteration of choices (and their presentation) is referred to here as nudging. Our decision-making context of interest are neonatal intensive care units (NICUs), particularly the challenging cases that concern the *limit of viability*. There, the NICU professionals make

decisions together with parents in a shared decision-making procedure. Our objective was to examine the presence of nudging in the shared decision-making in neonatology and elaborate on the respective moral challenges.
Results: Decision-making with respect to intensive and palliative care remains to contain elements of coercive paternalism regardless of the fact that shared decision-making procedures with surrogate decision-makers (parents, for the most part) are in place. The reason is that even though the neonatal professionals leave it up to the parents to decide - particularly within the *grey zone* of weeks 23+0 days and 24+6 days of gestation (the zone of *parental discretion*) - the way *how* the options are presented and *what* options are presented may steer the parental decision-making nonetheless. While parental understanding varies with parents and thus requires a personal approach, the process of information giving is subject to framing effect and other cognitive biases.
There are biases present also at the side of NICU professionals in the process of placing an indication such as when institutions create self-fulfilling prophecies by recommending intensive/palliative care based upon their institutional statistics (yet those vary considerably among high-income countries). Also, another example of a bias is the reliance on how the baby looks right after the delivery as this strategy of neonatologists for predicting survival was shown to be inappropriate. Furthermore, a Finish survey found that NICU professionals with the longest years' working experience were reluctant to administer steroids to mothers at the lowest weeks of GA to speed up the process of development of the infant.
With respect to moral challenges, nudging is not morally neutral. There are two key sources of ethical issues at the heart of nudging. The first one concerns the lack of transparency while the second concerns the background value judgments that are imminent whenever nudging is used for achieving a particular end. To solve the underlying conflict, a virtue ethics approach combined with the *accountability for reasonableness* (A4R) framework is suggested to guide the use of the tool of nudging. At the level of neonatal guidelines, it is argued that the presence of biases in the communication strategies ought to be recognized and dealt with along the lines of the four principles of A4R. Also, understood as an analogy to clinical judgment in the moral sphere, the virtue of practical wisdom is argued to be necessary when placing an indication at the bedside.
Conclusions: NICU professionals ought to use the tool of nudging transparently in line with their act of profession and their practically wise judgment.

Predictive testing and diagnostic testing – a dubious dichotomy?
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Predictive testing in medicine is on the rise. Due to an increasingly refined understanding of the underlying etiology of many diseases, tests for genetic or other biomarkers promise patients a preview of their future health. Longstanding examples such as Huntington's disease and breast and ovarian cancer due to BRCA mutations are complemented by additional neurological disorders such as amyotrophic lateral sclerosis and frontotemporal dementia, oncological disorders such as colorectal cancer or even psychiatric disorders. The rise of machine learning applications taking into account vast amounts of health-related data will further advance opportunities for predictive statements.
Within these contexts, the term 'predictive testing' is often used in a way that seems to imply a categorical difference from 'diagnostic testing'. In particular, 'predictive testing' usually characterizes instances where, based on the currently available data, the occurrence of a disease can be foretold with some degree of certainty before the actual occurrence or onset of any

associated symptoms. Supposedly, these elements warrant particular ethical concerns: predictive testing may create discrimination against patients, further medicalize ordinary life by extending the reach of the medical paradigm into the ordinary life of the healthy, create a new category of "predicted illness", contribute to increasing health care costs and misallocation of scarce financial resources within the health care system with a profound psychological impact on the predicted patients themselves. Concerns like these make it plausible that in many countries, including Switzerland, this difference is also enshrined legally with regard to counselling for genetic testing.
However, while we share many of these worries, the aforementioned issues do not seem to pertain exclusively to predictive tests but can often be levelled equally against many diagnostic tests. In our contribution, we thus aim to highlight why the distinction between predictive and diagnostic testing may not always provide additional explanatory power and that in fact we may have reason to forego this general differentiation to avoid its epistemologically misleading implications. To give a practical demonstration of this argument, we will consider two well-established cases of predictive and diagnostic testing respectively. For the predictive side we may turn to the archetypical test for Huntington's disease and juxtapose it with one of the simplest diagnostic tests of medicine: the establishment of hypertension through repeated measurements. Drawing on these examples, we will highlight how the supposed predictive test seems rather diagnostic in identifying a clearly identifiable pathophysiological correlate of certain future ill health, while the diagnostic test predicts, with varying probability, the future occurrence of severe illness like stroke, heart failure or chronic kidney disease. Of course, this is not to say that there are not crucial differences between the two. However, it seems to us that it is less the property of being predictive that warrants different treatment but rather a corollary of other, clinically more salient differences. We thus suggest to focus on distinctions that are of immediate clinical relevance, such as between tests which yield therapeutic consequences and test which do not.

Indication Creep and Covert Values

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One can find many different definitions of a medical indication. What is common to all of them is that an indication is a warrant, or justification, for an action. A contraindication is a warrant for not performing a particular action. The action might be a treatment such as prescribing a medication or performing surgery or some other procedure; or it might be any sort of diagnostic or prognostic test. The warrant is variously described so as to include facts, symptoms, signs, medical conditions, causes, and circumstances. What is not common to the various definitions is the force of the warrant. The warrant is variously said to be a valid reason, a reasonable basis, a suggestion, or something that makes an action advisable; hence, not a requirement. Contraindications, on the other hand, more typically carry the force of prohibiting an action, or equivalently, requiring the omission of the action.
"Indication creep" is a term that was originally associated with "off-label" use of drugs, i.e., prescribing drugs for reasons other than the indications for which the drug was approved, but has been expanded more broadly to refer to extending a particular intervention, diagnostic or therapeutic, to a broader population or to a different health condition than was accepted practice. Indication creep has been attributed to two major causes, each of which brings the risk of significant harms. First, proliferation of research and use of technology has enabled earlier diagnosis, often turning risks into diseases and lowering thresholds for defining disease; hypertension is one example. But the apparent good of early detection and treatment can expose

more people to harms from diagnostic tests and from treatments that would not have been previously considered. Extension of screening programs for diseases of low incidence will result in increases in false positives, resulting in a perceived need for further testing and even unneeded treatment. Simply being labeled as having a disease, even with no symptoms, can bring psychological harm. Second, financial incentives drive indication creep. The term "drug-mongering" has been used to describe the way drug companies have marketed new and profitable drugs by renaming certain conditions thought to be part of everyday life as diseases. Medical indications and contraindications must be interpreted and value dimensions such as these often remain covert in indication creep. The potential harms listed above are not only physical but also psycho-social and economic harms. Systems of payment for medical care that reward doing procedures can be incentives, even if unconscious, to accept indication creep in the name of early detection and prevention. In addition, research has shown that physicians facing irreducible uncertainty, which is unavoidable in medical practice, prefer to make the error of prescribing a drug that is not indicated rather than not use it when it is indicated. The problems of indication creep should be an indication for more research in and attention to the value dimensions of medical decision-making.

Medicalization of Chronic Pain

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Medicalization is the tendency to define and treat various problems in human living as medical problems. Treatment of pain rightly falls under the purview of medicine. Treatment of chronic pain, however, serves as a good case study to illustrate the complexity of medicalization, its benefits and disadvantages. Pain is chronic when it persists past normal healing time, lacks the usual warning function of physiological nociception, and lasts longer than three months. Chronic pain may be from cancer, abnormal healing after surgery or trauma, or neurological, visceral or musculoskeletal origin. The most recent revision of the World Health Organization's International Classification of Diseases (ICD-11, 2018) also includes a category of chronic primary pain, that which usually has unknown etiology. It is exemplified by such conditions as back pain, chronic widespread pain, fibromyalgia, and irritable bowel syndrome. Chronic primary pain is the subject of this inquiry.

Medicalizing chronic pain makes pain itself a medical problem, not merely a symptom of some other underlying medical problem. Medicalization comes about gradually from influences both outside and within the medical profession: from patient advocacy groups that have encouraged recognition and research funding; and from new theories of pain, the development of new treatments, and the establishment of pain clinics and an interdisciplinary specialty of pain medicine.

While this all seems good, medicalization is often criticized by scholars. Some argue that medicalization increasingly is turning all problems of living into medical problems. They cite as an example the evolution of an overly broad conception of health, as in the World Health Organization's definition of health as "a state of complete physical, mental, and social well-being." Such an understanding of health encourages people to reconceptualize all challenges of life and society as medical problems. Other critics argue that medicalization contributes to the power and dominance of the medical profession. It reinforces the authority resting on the perceived objectivity of the biomedical model; furthermore, it increases the economic power wielded by the medical and pharmaceutical industries, driving up the cost of health care.

This paper considers the benefits and disadvantages of the medicalization of chronic pain to patients, to the medical profession, and to society at large. Some have advocated for the

biopsychosocial model as the only adequate way to understand the suffering of people with chronic pain. But we must go further if we want to understand the depth and complexity of the issue. The experience of chronic pain exposes deeper questions of the meaning of pain and suffering; these questions take us beyond biological mechanisms, psychological experience, and sociocultural constructs. Chronic pain forces us to face the kinds of spiritual and philosophical outlooks that serve as the foundations of our deepest values and give meaning to human life. We here explore what these foundations have to teach us about both the usefulness and the limits of medicalization in dealing with chronic pain.

Reframing cancer

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Opportunities and costs of cancer treatment are on the increase. Opportunities are often framed as medical and costs as economic. Annual global oncology drug costs are exceeding 100 billion US dollars and projected to increase. Of course, these costs are also someone's income; and someone's medical opportunities induce opportunity costs on others in a limited health care system. In several countries there are lively debates on medical priority-setting related to the introduction of new and expensive cancer drugs and treatments, and whether they should be reimbursed by public (or private) health insurance.

In public as well as political and medical discourse, one of the dominant frames of the issue of new and expensive cancer drugs is that of tragic choices: Suffering and death by cancer is an intolerable evil for the individual patients, while the drug prices are intolerable to society. This gives rise to controversies from which no sustainable solutions emerge. In the most polarized expressions of such controversies, cancer patients and their representatives experience the situation as one of the government killing them by denying them access to the newest and most costly drug over the public health budget.

In this paper, we present a study of public media framings of the issue of priority-setting in relation to expensive cancer drugs in Norway. All articles published on the issue in major Norwegian newspaper from 2013-2016 were analysed by means of framing theory. Content analysis of the media coverage identified 9 different key frames but also a conspicuous similarity across these frames: The Norwegian newspaper media discourse adhered to a number of underlying premises, including that cancer drugs indeed are effective and that they have to be expensive; that patients and/or doctors own the truth about the disease (as being among the worst of maladies) and their views cannot be challenged; and finally that any health benefit for a cancer patient is considered an unproblematic, absolute good.

We argue that the perceived tragic character of the issue to a large extent results from the adherence to these underlying premises. Indeed, each of these premises should be subject to critical examination, empirically and normatively. A sober debate on new cancer drugs should acknowledge that the clinical benefit is often rather modest, and it should also boldly discuss the cultural perception that cancer ought to keep its reign as "the emperor of maladies". Accordingly, we will suggest possible reframings of cancer and the issues of priority-setting that might alleviate tragedy and promote sustainability in the health-care system.

Incidental Findings in Pragmatic Clinical Trials: Ethics at the Margins of Practice

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Pragmatic clinical trials (PCTs) are increasingly being used to address knowledge gaps for key stakeholders in health care systems. These gaps include comparing the effectiveness of already proven interventions, which is of great relevance to patients, clinicians, payers and health systems. PCTs are embedded in routine clinical practice and exploit technological efficiencies (such as harvesting data from the electronic health record rather than requiring additional data collection), making them less burdensome and more efficient than conventional research. Yet PCTs have encountered an array of ethical and regulatory complexities. One underappreciated issue relates to incidental and secondary findings (collectively "IFs") in PCTs. IFs are those findings that emerge as a result of the research process and could have clinical implications. While there is a substantial literature on IFs in radiology and in genetics, the applicability of this literature for PCT-IFs is unclear, in large part because PCTs are conducted at the boundaries of research and clinical practice. However, there are additional challenges. First, PCTs are often conducted without consent because the practices and interventions being assessed tend to be routine and accepted and there is minimal incremental risk or burden to patients. Second, PCT-IFs are likely to be identified by those without prior relationship to patients. Third, PCTs are of substantial scale, meaning management will involve considerable efforts for clinicians and health systems.

Given the complexities associated with PCTs, we examine several somewhat analogous domains to provide a background for normative analyses related to how PCT-IFs ought to be managed: IFs in conventional medical research, including biobanks and stored specimens; public health surveillance; environmental health research; clinical care; and quality improvement/quality assurance. Literature from these domains indicates several relevant considerations to help make ethically sound decisions about whether/not to return PCT-IFs including: What is the nature of the PCT-IF (e.g., severity, time-sensitivity, actionable)? How did the PCT-IF become known? Is the PCT-IF otherwise knowable? What is the relationship of the knower to the individual? Was consent provided for the PCT? Is the PCT-IF interpretable from data accessible to researchers? What is the time-lag from the time of testing to awareness? Is the patient currently in the health system? What is the nature of the health system? What is the feasibility of returning information, along with burdens and costs?

While these considerations are arguably all important, it would be premature to offer a single approach to managing PCT-IFs given the relatively limited experience with them. Nevertheless, with the rapid rise in PCTs, it will be essential to anticipate and develop means to address them. Here, empirical data from patients and other stakeholders should prove useful in informing ethical deliberations about PCT-IFs. Moving forward, it will be essential to develop a typology to guide decisions based on specific contexts and to prospectively manage PCT-IFS. Doing so will help fulfill the promise of PCTs to drive efficient generation of evidence to improve individual and population-level health.

To Die Well: The Phenomenology of Suffering and End of Life Ethics

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The paper presents a phenomenological account of suffering based on concepts such as mood, being-in-the-world and core life value which will better allow us to evaluate the hardships associated with dying and thereby may assist health care professionals in helping persons to die in the best possible manner. Suffering consists not only in physical pain but in being unable to do basic things that are considered to bestow meaning on one's life. The suffering can also be related to no longer being able to be the person one wants to be in the eyes of others, to losing

one's dignity and identity. These types of suffering become articulated by a narrative that holds together and bestows meaning on the whole life and identity of the dying person. In the encounter with the patient, the health-care professional attempts to understand the suffering-experience of the patient in an empathic and dialogic manner, in addition to exploring what has gone wrong in the patient's body. Matters of physician assisted suicide and/or euthanasia – if it should be legalized and if so under which conditions – need to be addressed by understanding human suffering and its positive counterpart, human flourishing, rather than stressing autonomy as the right to choose, only. In this phenomenological analysis the notion of togetherness, ultimately connecting to the political-philosophical issues of how we live together and take care of each other in a community, should be scrutinized.

Germline gene therapy of sickle-cell disease and β-thalassemia needs to change the gene therapy paradigm

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The use of the CRISPR/Cas9 technology for the genome editing of 3PN human embryos in 2015 as well as the unethical and controversial experiments which led to delivery of twin babies after knockout of the CCR5 gene using CRISPR biotechnology in 2018, have intensified debate on the use of germline gene therapy (GLGT) in humans. So far, GLGT has been recommended for use, when the techniques become safe enough for clinical use, after meeting several conditions. One of such criteria is that there are should be no alternative mechanisms available for parents wishing to have genetically related children without a specified mutation other than by GLGT. Ordinarily, recessive heritable genetic disorders are not eligible for GLGT because by using a combination of IVF and preimplantation genetic diagnosis (PGD), mutation free embryos can usually be selected for implantation leading to delivery of disease-free babies. However, sickle cell disease (SCD) and β-thalassemia, although caused by recessive mutations in the hemoglobin gene, appear to be exceptions to these requirements. Firstly, in contrast to most recessive single-gene heritable disorders, both are not rare, because estimated incidence of healthy carriers of these genetic disorders is as high as 25% of the population in endemic regions, including China and sub-Saharan Africa. Further, the risk that a potential opposite sex partner is also a carrier increases to 40% in some regions. Moreover, about 330,000 affected infants are born annually worldwide (83% with SCD, and 17% with thalassemia), and using recent mathematical modelling, this number is likely to increase to about 404,000 by 2050. Together with progress in therapy of SCD and β-thalassemia, including future use of somatic gene therapy (SGT), the number of potential parents who are homozygous for these mutations will significantly increase globally in the near future. For these categories of patients, the only possibility of having genetically related healthy children would be by use of GLGT. We explore this scenario from a long-term perspective and argue that the biggest obstacle to implementation of GLGT of SCD and thalassemia would not be technological, ethical, or social, but mainly economic. Due to the huge discrepancy between the very high cost of GLGT on the one hand, and socio-economic impact on lower-middle-income (LMIC) countries where this therapy is most needed. We therefore call for a change of the traditional gene therapy paradigm oriented towards individual patients with heritable disorders in richer developed countries, for a new funding paradigm and regimen oriented towards social justice, global ethics, and public health.

Borderline medicine and incongruent ethics: The case of UK occupational medicine

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Occupational medicine (OM) is one of the areas of medicine where a doctor is said to have "dual obligations". In the United Kingdom (UK), therapeutic interventions are not provided by OM services, except for emergency first aid and work-related immunisations, so arguably we could describe this discipline as being "borderline medicine". The obligations are primarily owed to workers and employers, but also to other stakeholders. The tensions arising from owing obligations to different parties with sometimes divergent interests, at the same time, may lead to ethical conflict. For example, I will argue that existing UK guidance places conflicting and incongruent ethical demands on occupational physicians in some of their roles, particularly when they conduct an independent assessment for pension funds. However, I maintain that one should also look *beyond* such dual doctor obligations when trying to unravel the ethical issues and conflicts in this medical discipline. I will propose an analytical framework based on the different functions or *roles* that OM physicians undertake. I will argue that this provides a clearer methodology in identifying, and addressing, the reasons for these ethical difficulties.

Retaining Moral Responsibility in the Face of Medical Technology"

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Technological innovations in healthcare, perhaps now more than ever, are posing decisive opportunities for improvements in diagnostics, treatment, and overall quality of human life. Personal health monitors are alerting patients to their individualized needs. Automated systems are helping hospitals, which are often chronically understaffed, to more efficiently meet high demands while cutting costs. And the use of big data will soon generate specific recommendations for general lifestyle choices. Indeed, these sorts of developments are beginning to receive noticeable attention in recent medical and bioethics literature. What has yet to be substantively addressed, however, is the impact of emerging technologies upon patients' and healthcare practitioners' sense of agency and moral responsibility. For example, does the introduction of artificially intelligent diagnostic and treatment systems, such as Watson for Oncology, undermine the physicians' role in recommending therapy options? Who should be held responsible when a machine costs us a life, and who (or what) *can* be plausibly held responsible? With this project, I aim to establish important ethical implications for our development and use of emerging medical technologies. I survey some ways in which technology may be undermining the agential status of both patients and physicians. Given the common conceptual link between moral agency and moral responsibility, what follows from our undermined agency in medical contexts, I argue, are difficulties in locating responsibility—say, for medical errors. While innovative technologies are, no doubt, providing exciting opportunities for improved healthcare, it may be that our use of such advancements will pose potentially insurmountable ethical obstacles. If our ability to locate moral responsibility becomes increasingly obscured with the rise of medical technology, we are left with a great dilemma: we may need to scale-back our use of state-of-the-art systems, and thereby lose out on such benefits as improved quality of care and increases in lives saved; otherwise, we might need to loosen our commitment to identifying moral responsibility when a life is lost. Although this dilemma will likely continue to present itself in various realms of healthcare, I offer some suggestions for how it might be best addressed. In short, we can assure that responsibility—and perhaps even blame—will be taken by attending practitioners, even where they were not strictly responsible for an outcome. Alternatively, as medical technologies continue to develop, we can

cultivate novel mechanisms for holding machines responsible. In other words, while agency may be undermined, we can retain moral responsibility in the face of medical technology.

Checklist for applying to RECs: ethical and legal issues post GDPR

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A research protocol involving human subjects and/or human samples has both a scientific as well as a social value, which includes the effect research has on the research subjects themselves and on the society as a whole. However, the plethora of the international legal instruments, which are available for the compliance of research to basic legal and ethical requirements, produces a "regulatory polyphony". This, consequently, increases the complexity of the researchers' task to achieve ethical and legal conformance for their projects, as they are confronted with numerous overlapping, and often contradictory, provisions. Therefore, the existing pluralism of the regulatory and ethical framework, instead of assisting it often undermines the social value of research itself.
This presentation follows the structure of a – recently under review- paper which aims to serve as a "roadmap" for researchers who wish to conduct their research. A checklist may also serve as a guide for members of ethics boards, when screening new or ongoing studies. Some of the ethical and legal issues examined include among others the following:

a. International legal instruments
b. Informed consent procedures
c. MTA/DTA agreements
d. Quality control procedures for material transfer.

The aim of the presentation is to offer a general overview of the criteria REC's use on an international level in order to screen the legal conformity and ethical validity of a research project. Specific issues on consent as a legal basis for conducting research, the problematic of re-consent, sometimes being impossible to trace the participants if for e.g. they have moved or passed away concerns on consent fatigue etc., will be examined also under the changes GDPR brings across EU member states. Finally, the derogations Member States have foreseen on privacy related issues in the field of research (on the basis of a.89 GDPR) will be presented on a Pan-European level comparative basis, provoking the stimulation of a dialogue among scholars of their relevant country related experiences.

Two perspectives on dual relationships

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In this session I will present and discuss findings from the paper "Encountering ambivalence – A qualitative study of mental health nurses' experiences with dual relationships", previously published in the journal Issues in Mental Health Nursing.
Nurses and other health professionals are obliged to set professional boundaries in their relationships with patients. Dual relationships, like friendly relationships with patients that are pursued outside of working hours, are commonly prohibited by legislation and professional codes of ethics, but some nurses and health professionals still engage in them.
A thematic analysis of qualitative interviews with six Norwegian mental health nurses, who had engaged in dual relationships with patients, revealed that the nurses experienced ambivalence regarding how they see the patients, their assessment of the dual relationships and how people around the nurses react to the relationships. Ambivalence was characterized by contradictory

and indeterminate thoughts and attitudes toward patients and dual relationships. Results indicated that dual relationship decisions were complex and highly contextually dependent.
The nurses' perspectives on dual relationships are contrasted by Norwegian regulators' emphasis on asymmetrical power relationships, the patients' vulnerability, and dual relationships as a proof of irresponsible conduct and unprofessional judgement. The nurses in the study claimed a sense of reciprocity in the nurse-patient dual relationships, whereas disciplinary cases reveal regulators' insistence on health professional's sole responsibility in managing professional boundaries. The nurses' perspective seemed characterized by a focus on specific nurse-patient relationships, while regulators' perspective might focus too little on context and particular circumstances.

A case-based examination of obligations to reinstate female circumcision following childbirth in the United States

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Many immigrant women receiving perinatal healthcare in the United States may have previously undergone female circumcision in their natal countries. This presentation explores an ethics consultation of an immigrant Somalian woman who received perinatal healthcare in the US for her fifth pregnancy. During the child birthing process the mother experienced vaginal tearing requiring an intervention which ultimately changed the function and appearance of her genitals. Following the delivery of her child the patient and her husband became aware of the situation which occurred. The patient, husband, mother of the patient demanded that she "be returned to normal". Thus, a clash of values and culture occurred. Ethics was called to consult and to mediate the conflict. The patient believed she was not provided the care which she and others wanted, while staff experienced confusion, and moral distress along with a reluctance to engage the patient in conversation regarding her wishes and values.
This unique case will be explored using narrative inquiry from de-identified information obtained in conversation with the patient, her husband, her mother, and hospital staff following the request to reinstate the condition of female circumcision.
Subsequent strategic efforts to collaborate with leaders in the Somalian community such esteemed religious leaders, University Professors, along with focus groups, were engaged to obtain information from women reluctant to speak openly with healthcare providers. This approach met with positive change in approaches to offering perinatal services, which are simultaneously culturally sensitive, ethical, and in keeping with American legal standards.

Follow up on rejected euthanasia requests

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The Dutch End- of-Life clinic is a last resort for patients who have a request for euthanasia that is denied by their own doctor. The End of Life clinic (a misnomer, since it is not a clinic), is willing to perform euthanasia if they judge the request complies with the due care criteria stated in the Dutch Law. Since their start in 2012, this 'clinic' has become increasingly sought by patients. Most requests are denied however. We wanted to know what happens to patients after their request is denied. We did a follow. Up research, 3, 6, and 12 months after rejection, by telephone interviews. We will present our preliminary data on this follow up research.

The precision paradox in personalized medicine: How can uncertainty be reduced when statistics do not apply?

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Novel technologies have led to the emergence of the biomedical vision of precision medicine (or personalized medicine). Such technologies are DNA sequencing and analysis, molecular 'omics', tools for 'digitizing' human physiology, computational modelling, organ-on-chip technologies and machine learning (artificial intelligence).

A main vision in precision medicine is to develop diagnostics and treatments that pertain uniquely to individual biology or a small stratum of individuals - as compared to a much-criticized "one-size-fits-all" medicine based on statistical averages of heterogeneous population samples. One assumption in this vision is that personalizing the management of individual health, has previously been regarded as the "art of medicine," can now be made more scientific and quantitative, for example through machine learning. However, as the number of research subjects or samples approaches one (n --> 1) and the number of variables that are measured or therapeutically targeted in each individual increase, we face what can be called "*The precision paradox*": It will be difficult or impossible to develop clinical studies that apply specifically to the individual case based on traditional statistical methods. As we know more and more about a smaller and smaller population (eventually n=1), uncertainty may paradoxically *increase* rather than *decrease* - at least in an interim phase. In particular, what may increase is *strict uncertainty*, defined as uncertainty where the event space is known, but not quantifiable. This uncertainty may be called 'qualitative uncertainty' as it is not quantifiable.

While quantitative uncertainty is a theoretical "room", which has been densely furnished, the theoretical "room" of how to consider and reduce qualitative uncertainty so as to make precision medicine more predictive and scientific is relatively unfurnished. At the same time, personalization is not new to medicine and human beings were able to explain and predict events in the world before the advent of statistics.

Against this background, we here therefore aim to point in the direction of a framework for reducing or managing "qualitative uncertainty" in precision medicine, using organ-on-a-chip technology as a case. When and in what ways - if any - can non-statistical evidence and methods for analyzing it reliably be taken to reduce qualitative uncertainty and create valid predictions? By what criteria, for example, can narratives (case histories) be regarded as evidence for predictive models?

Rather than providing definite answers to these questions, we first aim to map and systematize previous epistemological theorizing relevant to the problem, to point in the direction of future work and invite a fruitful discussion on this burning theoretical issue.

Bullying, Harassment and Undermining in Medicine Through the Lenses of Moral Failure and Morality of Violence Theories

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The complex phenomenon of bullying in medicine has been studied by sociologists and educational scholars since the 1950s within the framework of the socialization or acculturation of doctors (Berger, Merton, Becker). Hafferty et al. in the 1990s connected bullying, harassment, and undermining behaviours with a 'hidden curriculum' (HC), i.e. unconscious modelling of physician conduct not transmitted through formal or explicit processes. Now

almost universally recognized as highly pernicious by international governing bodies such as the GMC, AFMC, and AMA, abusive and asymmetric power relations in medicine have been blamed on structural and institutional factors and identity formation rituals designed to communicate competence to the general public and other professionals. Research aimed at understanding bullying has been primarily conducted along pragmatic lines – reporting prevalence in cross sectional studies of attitudes and behaviours, and cataloguing measurable psychological effects (burnout, depression, suicidal ideation, etc.). Although identified as a significant ethical concern in medicine, not enough attention has been paid to bullying as an individual and collective moral failure, or as a form of moral violence. This contribution adopts insights and theoretical work from Johan Galtung, Kenneth Boulding, and Mahatma Gandhi to explore the moral dimensions of bullying behaviors in medical experiences.

The response of the WMA, AMA and other professional medical associations to the medicalization of assisted suicide and euthanasia.

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The medicalization of AS/E – once legalized – is universal. Surprisingly, this assignment of the full responsibility for AS/E to physicians is rarely discussed, let alone questioned. While legislatures and courts considering decriminalization of AS/E always debate and evaluate the social and legal ramifications of legalizing AS/E, they rarely consider the impact of such legalization on physicians and the medical profession as a whole. Contributing to this medicalization is the role taken by a number of medical professions themselves who have publicly tolerated this medicalization (by changing their code of ethics to go "neutral" on medicalized AS/E) or actively promoted this medicalization. In this presentation we briefly review the ongoing debate in the American Medical Association and the efforts of the Royal Dutch Medical Association and the Canadian Medical Association, which have already embraced medicalized AS/E, to have the World Medical Association abandon its opposition to this medicalization.

Natality between Philosophy and Medicine

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Philosophy and Medicine are related since the beginning of Western history. In Medicine, Hippocrates' principle of doing good and avoiding harm is constantly quoted. In Philosophy, Socrates, who preached that it was better to suffer from evil than to practice it, inaugurates a way of philosophizing named "maieutic" in honor to his mother, the midwife Phaenarete, that is, the art of giving birth to the idea of others.
Life and Health sciences assume a conception of the human condition that can be explained and debated philosophically. Traditionally, we privilege the philosophical debate of the mortal condition in human existence, in its finitude and structural terminality, to the detriment of our natal condition. Little attention and reflection are devoted to the structural character of birth, the contingent fact of being born and its respective initiative that follows our existence in its articulations with health care.
The aim of this work is to present the contribution of two contemporary women philosophers, taking into account the fact of birth in our unique existence and its strength to persist, biographically, in successive rebirths throughout our life. It is an existential perspective,

through the political thinking of Hannah Arendt and the poetic thinking of María Zambrano, that allows us to consider our condition not only as mortal but also as natal. In the work of these women thinkers, birth receives the status of human condition of our worldly existence.
The fact of had been born is a condition of our human existence, the ever-contingent ability to begin something new in the world in which we coexist with other people. Natality corresponds to freedom of beginnings to Arendt. According to Zambrano, the human being is not completely born, truly existing only when it gives birth to itself as a unique individual in coexistence with others.
The attention to human life as born but also as a nascent existence proposes a matter among fertility considerations and demography and raises the question: what does it mean to be born? Putting into perspective the life between birth and death, the natal-mortal condition that constitutes our worldly existence is emphasized. The existential descriptions of Arendt and Zambrano can contribute to the contemporary debate between pro-natalism and anti-natalism. The issue the women authors present precedes and follows this debate, which usually is polarized in positions for and against, no matter how different the arguments in each pole.

Between the Individual and the Family: The Family's Role in Decision making at the End of Life

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In recent years, there is a trend of shifting the end of life palliative care to community setting. This trend reflects both patients' preference to die in their homes, and institutional preference.
In Israel, despite the process of shifting the actual place of death to the patient's home, where the primary care giver is a family member, the family members have no legal status in the process of end of life decision making process. The prevailing approach grants autonomy of the patient and enables him to make decisions related to his body and allows him to share or prevent the participation of his family members in the process.
Although the natural expectation, that family members will know the preferences of their members at the end of their life, research findings reveals low degree of congruence between patient preferences and family preferences among families that were required to make medical decisions at end-of-life situations. This reality arises many ethical dilemmas with which professionals are forced to face.
The current lecture will present a theoretical review alongside, a presentation of various models for dealing with ethical issues. We will emphasize the importance of the transition from a patient focused decision-making, to a more comprehensive model, which views the individual as part of a family system, and therefore takes into consideration all the factors related to coping.

Against exceptionalism in healthcare decisions (when capacity is in doubt), and how to get rid of it

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Decision making regarding medical treatment and other healthcare services is − for good historical reasons − focused around the interconnected concepts of *consent* and *autonomy*. In

modern healthcare systems, growing populations of patients are in a position where their capacity to consent is doubtful. This may be due to illness, extremely advanced age, severe trauma, the nature of prior procedures, medication or other factors. In problematic cases, various legal systems provide different solutions: family, appointed representatives, medical personnel or even courts may be empowered to make decisions that are often time-critical. These people and institutions are supposed to employ various techniques, such as *substitute judgement* to arrive at a conclusion that would respect the person subjected to the decision. However, outside of healthcare context, if a decision is being made on behalf of such a person lacking capacity, the abstract notion of "person's interests" or similar may be employed.
In my presentation I take the following premises, which I will justify shortly:

1. That some interpretation of the mainstream (principlist/coherentist) bioethical discourse is an indispensable expression of the values of a pluralistic democratic society.
2. That the respect for persons – their values, wishes and preferences is valid not only in the healthcare context.
3. That human flourishing and well-being, however defined, must take into account the respect for persons.

I use these premises to argue that, firstly, we need to abandon the sharp distinction between medical and non-medical decision making, and secondly, that both contexts require similar, unified, and integrated process of determining values, preferences and wishes. And do so regardless of the capacity judgements if these decisions are to take full account of respect for persons. In practice, my argument would affect both healthcare practice, where decision making is not necessarily always very serious or life changing, and oftentimes might be done more like other daily decisions of similar importance, and non-healthcare practices where significant decisions require more serious investigation of reasons for them and how they take into account the respect for the person who is subjected to it.
In short, my argument I will oppose the application of *volenti non fit inivria* to both contexts, as well as paternalistic assumption of what should be considered the persons' interest in life in general.
In recent years, we have seen examples of positive aspects of medicalisation. I would argue that there might be a case for bioethicisation.

Ethico-Political Aspects of Conceptualizing Screening: The Case of Dementia
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In 1968, the World Health Organization published James Wilson and Gunnar Jungner's report *Principles and Practice of Screening for Disease*. This report has been central to screening program assessments and is sometimes referred to as the "gold standard" (Andermann et al. 2008). It formulates ten principles for assessing screening programs and contains definitions of screening and related concepts. Screening, Wilson and Jungner state, is concerned with "unrecognized symptomatic" and "pre-symptomatic disease" (1968). "In general," they also add, "we have taken the definition [of screening] to imply a relatively simple (though not necessarily unsophisticated) method of case-finding" (Ibid.).
Since 1968, new criteria or principles have been added and *distinctions between certain types of screening* have been elaborated upon, i.e. population-based screening, prescriptive screening, and opportunistic screening. Other concepts and distinctions have also enabled a *distance from the concept of screening*, as when it is emphasized that case-finding should be understood as different from screening (see for example Ransom et al 2018).

This presentation examines such conceptualizations of screening with a focus on what different conceptualizations help do; how different distinctions and delimitations of concepts used have ethical and political implications. We specifically examine screenings/case-finding of dementia and explore what we see as a sometimes an intimate bond between the *how* and *what* of screening. The definition of the phenomenon (the what of screening), we suggest, is sometimes drawn into the ethical, political, and practical dimensions that the principles are aimed to clarify and control (the how of screening, how it should be performed). We also show how different conceptualisations of screening (the what of screening) can open up an opportunity to rethink which ethical assessments should take place: these conceptualisations have different ethico-political implications (the how). Furthermore, as a certain set of criteria has become part of the "gold standard" for screening and recur in several national screening assessment models, these criteria also help shape which practices become accepted as screening practices. This, of course, is not strange. However, and to put this a bit provocatively: for proponents of a certain use of a screening test, it might be preferable not to call the practice in which this test is used a screening practice, if it is likely not to fulfil the screening assessment criteria. The dementia discussions are illustrative in this regard.

Moral status of the brain-dead patient: Defying the Dead Donor Rule
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The Dead Donor Rule (DDR) guides the practice of organ transplantation, stating that living organs may only be procured from dead bodies. What enables us to consider a dead brain patient as dead, and therefore, the optimal organ donor, is the 1980's legal definition of human death by neurological criteria: the irreversible cessation of all functions of the entire brain.
However, numerous academic articles have determined prolonged life spans in dead brain patients, which effectively prove that patients with this diagnosis are not dead, and that all functions of the entire brain do not cease: they legally conform to the DDR, while not being biologically dead.
What is put forward in this presentation, is that, even though dead brain patients are not dead, their irreversible clinical condition severely compromises their moral status, not losing their personhood, but altering their moral status to allow the donation of "life". Based on current philosophical models of moral status, I propose and explain what the moral status for brain dead patients is, allowing for organ donation without incurring in the violation of a fallacious deontological constraint, such as the DDR.

To let Die or not to let Die? Decision making, Medical Practice and Court Rulings in Light of the Dying Patient Act in Israel
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The Israeli Dying Patient Act ("the law") came into force in 2006, representing a wide consensus between conflicting views promoting sanctity of life agendas on the one hand, and liberal respect for patient autonomy positions on the other. Prior to the law, courts, supported by governmental guidelines ruled oftentimes, in favor of preventing life sustaining treatment including resuscitation, food, fluids and dialysis (that is, passive euthanasia) for patients with no hope of prolonging life, in case the treatment was considered futile, for the purpose of alleviating pain and suffering. Its mere enactment was an important acknowledgment of the

right to die in the sole Jewish country in the world, the religious of which praises the sanctity of life above other values. At the same time, the law and subsequent clinical practice had in fact worsen the situation of patients who are not defined by it.

The law defines a dying patient as suffering from incurable medical condition, and her life expectancy does not exceed six months, regardless of treatment. It provides a valuable guideline for practicing physicians regarding the type of care, which may be prevented from dying patients under the law. If legally competent, a reasonable effort should be made to convince the dying patient to receive oxygen, food and fluids, yet she can exercise their right to die. In an incompetent dying patient, care aimed at the untreatable medical problem (i.e., dialysis, chemo and resuscitation) should be prevented yet other kinds of care (i.e., food and palliative care) may not be prevented.

Patients who do not adhere to the six months timeline, are not regulated by the law. Those include demented elderly people or patients diagnosed with ALS or other incurable chronic conditions. Even if they explicitly express their wish to end their life, such patients find themselves oftentimes unable to do it in Israel. If they (or their families/friends) are familiar with international organizations providing assisted euthanasia in countries that allow it and can afford the trip and service, sometimes find peace there. In most cases, however, Israeli physicians and nurses find themselves reluctant to keep providing them futile treatment. Court rulings, on their end, tend to approve decision making against those patient's will to die and in favor of keeping them alive, if not defined as dying by the law.

In light of this complex medico legal situation, several governmental guidelines and court rulings from the past few years will be presented which indicate a possible transition from the law, by allowing for passive euthanasia in practice, using gradient decrease of resuscitation and oxygen saturation in certain conditions. That said, a recent report of Israel Medical Association (published December 2018 in Hebrew) provides surprising results. The survey analysis indicates that out of 3000 physicians, only half up to two thirds of respondents are either willing to provide painkillers in a deadly dosage or stop life-saving treatment, in different case scenarios, for patients defined by the law, eligible by it to end their life if so they wish, and hold the right documents for that purpose. These findings, I argue, demonstrate the challenges of the law in providing clear guidance to healthcare teams considering end-of-life decisions, and its poor implementation in hospitals, rather than points out distinct pro-life views of practicing physicians and nurses.

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