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ABSTRACTS

Belgian Muslim Women and Treatment Decisions at the End of Life

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Background: This paper is embedded in an ongoing PhD project on attitudes, beliefs and practices of Moroccan Muslim women in Antwerp (Belgium) towards death and dying. In a few decennia, Islam has become the second largest religion in the country. Today, the medical advances have constituted several dilemmas at the end of life. In the context of the Belgian debates on end-of-life care, which is still deeply influenced by contemporary secular/Western/Christian approaches, the views of Muslim women remain understudied.

Aims: The aim of this article is threefold. First, we seek to describe the beliefs and attitudes of middle-aged and elderly Moroccan Muslim women toward active euthanasia, withholding and withdrawing life-sustaining treatments, and pain- and symptom control. Second, we aim to identify whether differences are observable among middle-aged and elderly women's attitudes toward these treatments at the end of life. This comparative aspect of the beliefs and attitudes of the first and second generation Muslims is interesting given the fact that in Belgium this second generation shows more socio-economic diversity and that one can assumed that they have been much stronger influenced by Western ideas, as they have been brought up in a Western society. They are no longer raised in a homogenous, rural, traditional Islamic environment and live less isolated from the broader Belgian society, compared with the first generation Muslims. Third, we aim to explore the role of religion in their attitudes.

Methods: Qualitative empirical research was conducted with a sample of middle-aged and elderly Moroccan Muslim women (n=30) living in Antwerp (Belgium) and with experts in the field (n=15). All interviews were transcribed, coded and categorized using Grounded Theory methodology.

Results: Euthanasia and assisted suicide are vehemently rejected, however, with regard to non-treatment decisions and pain control different perspectives exist. These ethical dilemmas are strongly interpreted from within a theological and more specifically an eschatological framework: God governs illness and health, life and death; it is unacceptable to interfere in God's divine plan. We found hardly any differences between the attitudes of the first and second-generation Moroccan Muslim women nor between the guidelines in the international normative Muslim sources and the actual attitudes of our participants.

Conclusion: Our study reveals that religious beliefs and worldviews have a great impact on the ethical attitudes toward end-of-life issues. Theological and more specifically teleological considerations that centre on God's almightiness and the belief in afterlife seem to be very crucial for Muslims. Rather surprisingly no radical differences were found between the views and attitudes of middle-aged and elderly Moroccan Muslim women, despite their often very different socio-economic position, educational level and integration in western society.

Emerging technologies, emerging moralism?

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The political trend of the responsabilisation of the individual has resulted in a discourse of health moralism in healthcare ethics. In this discourse, the reasons for not complying with the standards of healthy behavior are found within the individual, her choices, or moral; and consequently, she is taken to be blameworthy or accountable for her behavior. This moralism can be reflected with Samuel Scheffler's notion of "moralism of responsibility", an established form of political moralism that uses a simplified and highly moralized discourse

of personal responsibility to lay the causes of poverty on the poor themselves; and enables the well off to feel that they can take credit for their own success without needing to be troubled for the less fortunate. However, this view is in direct conflict with the outcomes we know the social determinants of health and effects of scarcity have: the genuine opportunities of making “the rights” choices vary according to individuals’ and group’s socioeconomic and cultural position in the society.

In this paper, I discuss the relation between the responsabilisation of the individual and the emergence of new technologies in health care. Along new opportunities brought by new technologies, the overall range of choice that an individual can make related to her healthcare is likely to increase. The individuals who most benefit from this increase of choice is most likely the same who already now has the best resources to take responsibility for their health.

The aim of my argument is not to oppose the new opportunities brought by new technologies. Instead, the main statement is that these new opportunities should not accelerate the prevailing health moralism. Despite the new technologies, health and disease will continue to be a political, not a mere technological and scientific question, and people with little social determinants and living in scarcity will continue to have lesser opportunity to make the “right” choices. For example, knowledge of risk does not necessarily contribute to increased ability to control one’s life.

Genome Editing Outside Professional Settings: New Challenges to Governance

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Genome editing techniques, especially CRISPR-Cas9, hold the prospect of unprecedented medical, agricultural and industrial applications. At the same time, these techniques may and will most probably be increasingly employed also outside educational, research and commercial institutions. In my presentation, I will assess two such cases: hobbyists and bioterrorists. It is argued that each of them brings about new extrinsic ethical issues pertaining to biosafety and biosecurity, respectively.

[I] Biohackers and Do-It-Yourself Biology (DIYbio) refer, roughly speaking, to hobbyists founding molecular biology labs and doing biological engineering outside professional settings. The DIYbio.org website mentions 72 local groups, labs or hackerspaces (i.e. community-operated physical places where people can meet and work on their projects) worldwide. The DIYbio communities are mostly concerned with education events (such as public talks and courses) and common projects involve basic molecular biology experiments. Yet there are several projects that are advanced. One example is the Glowing Plant Project(s) where a *Luciferase-luciferin* gene is inserted into a model plant (*Arabidopsis thaliana*) to make it glow. Noteworthy is that biohackers have developed workarounds to replace standard lab equipment which is too expensive for personal use. The new extrinsic issue and challenge to governance is concerned with the due biosafety requirements and procedures for genome editing outside professional labs. Is self-governance (or -policing) enough? There currently remains regulatory uncertainty about whether or not genome editing falls under the GMO regulatory framework in the EU. This situation works as a hindrance to research and product development, and the European Commission is expected to take a stance on the question in the near future. If genome editing does not fall under the framework, then there are no permit or notification requirements for conducting genome editing either at professional labs or as part of biohacking projects.

[II] Genome editing techniques together with synthetic biology introduce new risks of design, construction and use of engineered (or partially constructed) pathogens for malicious purposes. An increase in the relative risk of bioterrorism follows as an unintended side-effect from (1) the spread of the required know-how which results from an ever-more common and wider use of the genome editing techniques, (2) the better availability of techniques, (physical and computational) tools and biological parts that results from the falling price of DNA sequencing and synthesis as well as the ease and precision of genome editing, and (3) the new technical possibilities which include “resurrecting” disappeared pathogens (such as the Spanish Flu) and new kinds of pathogens with higher virulence and resistance to the known drugs. The pressing novel extrinsic issue and challenge to governance is how to assess and manage situations where there are possible but difficult-to-quantify harms and possible rogue individual or groups’ actions that are difficult to supervise.

A realistic ethical ideal of non-human animal use in science, (an attempt to define)

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The question of animal use in science brings a lot of emotions, whether discussion takes place in social media, television or in Academia. We can hear opponents of animal experiments calling researchers who conduct them “cruel” or “sadistic” and animal experiments’ supporters claiming that their opponents tend to choose animals over humans or that all “true” scientists support their position (otherwise they cannot call themselves scientists). There are also few misunderstandings and misconceptions concerning concepts like “necessity”, “vivisection” or “euthanasia” which seem to be crucial in bioethical debate on non-human animal use in science.

Among philosophers and bioethicists supporting animal rights (or animal interests) we can find very different approaches to animal experiments. Some of them try to list criteria which will allow to draw the line between those animals which deserve our moral concern and those which do not, or to define those which not only deserve our moral concern but also have some basic moral rights and valid moral claims against us. Although all of them claim that non-human animal do matter, the standpoint of Peter Singer is very different from Tom Regan’s point of view and none of them would agree with Gary L. Francione. When talking about animal use in science – which criteria could be taken into consideration and is there even a chance for agreement?

The Moral Biomedical Enhancement and the key role of the context

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The main aim of this work is to provide an analysis of the lively debate about new opportunities offered by Moral Biomedical Enhancement. We live in a dangerous time, we have a power that we’ve never had before and we face unprecedented challenges. We must deal with environmental problems (such as climate change, global warming, extinction of other species, glacier melting, acidic rain, raise of greenhouse effect, etc.) and with another kind of man-made threats to the humankind and to the Earth.

Nuclear “megaterrorism” and the potential hazards stemming from microbiology and genetics, as pointed out by Sir Martin Rees, are some of the most dangerous risks in our time. Anybody may someday produce a biological weapon in a backyard laboratory. It is not just a

nightmare, but a worrying reality: the first bioterror attack was in 1984, when some followers of the Rajneeshee cult contaminated some salad bars in ten restaurants, in Oregon, with salmonella. In the early 1995s the Aum Shinrikyo in Japan released the nerve gas sarin in the Tokyo subway. In 2001 two US senators and several media organizations received some envelopes containing anthrax spores. In 2012 two teams of scientists in the United States and in Netherlands engineered the H5N1 bird flu virus to spread more easily among mammals, because they realized that a similar kind of virus could have been developed in nature shortly; therefore they wanted to prevent it.

This unstoppable scientific advance make us more powerful, but greater power requires greater responsibility. So, are we morally ready to manage all of this? Our natural moral psychology is not enough, it induces us to focus on the immediate future and only on our family and close friends, but we live in a globalized world and we must deal with its problems.

The idea of Moral Biomedical Enhancement is that the traditional methods to improve our morality are lacking, hence we should introduce some new biochemical enhancers. Starting from J. Savulescu and J. Harris' points of view, we'll analyze the "objection of the context". They both believe that we face enormous dangers and we need to enhance our moral competence, but J. Harris claims that every moral choice depends on the context that is influenced by several factors, therefore it is impossible

determine the right thing to do a priori. The real issue at stake is a picture of what is "moral agency". According to Harris, our action is not only in the neuron, so enhance some "prosocial attitudes" is useless if not disadvantageous. Similarly, H. Wiseman underlines the complexity of moral functioning that involves phenomena that have many interacting influences (the *mélange* problem). Like Harris, Wiseman thinks that there is no direct cause-and-effect relationship between biology and moral functioning. Every moral choice is intrinsically linked to the context: this is one of the most difficult hinder of Moral Biomedical Enhancement.

Animal Research Ethics

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Ethical issues regarding the use of non-human animals in biomedical research have traditionally been thought to fall under animal ethics. Within animal ethics, the central issue has been the general justifiability of animal experimentation, typically with reference to animal rights or liberation. In recent years, however, the ethics of animal research has been increasingly discussed in the context of research ethics rather than animal ethics. The emergence of *animal research ethics* has moved ethical issues in animal research from the margins of medical ethics to its centre. More importantly, it has reframed many of the ethical issues involved. Instead of focusing merely on the justifiability of animal research, animal research ethics is concerned with issues, which parallel human research ethics, such as agency and assent/dissent, harms and benefits, vulnerability, and justice. Using non-human primates as an example, I briefly survey these research ethics issues and their applicability to non-human animals, arguing that their applicability depends strongly on the moral status of different species.

Ethical concerns resulting from the advances in life-sustaining technologies: the transformation of the “*ars moriendi*” to “medicilazed death”

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Public health improvements, medical advances, and technological developments have increased average life expectancy across the world. According to the studies, the percentage of people aged 65 or older, which was 8% in 2010, will be 16% of the world population in 2050; the aging population is estimated to increase 250% in developing countries and 71% in developed countries between 2010 and 2050.¹ Although living longer represents a desirable aim, higher life expectancy significantly increases the need of healthcare resources, desperately escalates the suffering at the end of life, and dramatically change death and dying process.²

Death is a natural and inevitable phenomenon. The central issue surrounding death and dying is mainly about how to make a *good death* possible. The perception of *good death* is subjective; it may be a painless or a sudden death for some, while it might be a death occurring at home or at a young age for others.³ Ultimately, everyone wishes to get his/her own *good death*, and the primary ethical approach should be to give each person the opportunity to fulfill his/her own *good death* with the balance between the expected benefits and burdens.

Nevertheless, the advances in medical technologies have intensely increased medical interventions in death and dying process. Lydia S. Dugdale regards the medical engagements as the deterioration of the *Ars moriendi* (art of dying) and the emergence of *medicalized death*.⁴ The *Ars moriendi*, also known as the *art of dying*, is a Catholic Church concept originating in the fourteenth century during the outbreak of the Bubonic Plague (Black Death) which killed millions of people in Europe.⁵ The Church strived to prepare people for death through a religious aspect that “the dying faithful should not fear death, since God is in control of every moment, including death,” and a good death can be achieved “by leading a repentant and righteous life.”⁶ Even though the *Ars moriendi* represented a religious approach to explain how a good death is possible and why dying should not be feared, this perspective deeming death as a natural phenomenon influenced secular approaches as well for many centuries until medical and technological advances gained sufficient ability to impact the time and manner of death.⁷ Medical and technological improvements have created a new perception that death is an enemy which must be defeated at all costs.⁸ The combination of this approach and the sense of playing god has caused the overuse of life sustaining-treatments which has sometimes come out as a medical torture.⁹

In this view, the transformation from the *Ars moriendi* to *medicalized death* have generated certain ethical and legal challenges surrounding the issues of *where to die*, *how to die*, and *when to die*: whether to die at home or in a healthcare facility; whether to receive pain management care or aggressive treatment; whether to be on comfort measures only or life-sustaining care. The implementation or omission of each of them with each option’s medical benefit and harm and financial burdens to the patient, family, or society engenders particular consequences which may not be congruent with ethical principles. Recognizing the inevitability of death, accepting the limitations of medicine, avoiding the overuse of medical technologies, and acknowledging the scarcity of resources may help to lessen the ethical concerns of life-sustaining technologies.

Notes

¹ U.S. National Institute on Aging National Institutes of Health and World Health Organization, *Global Health and Aging* (National Institute on Aging National Institutes of Health and World Health Organization, Publication no. 11-7737, 2011), 2-6.

² The Hasting Center, *The Goals of Medicine: Setting New Priorities* (The Hasting Center, 1996), executive summary.

³ Stephen R. Latham, "Pluralism and the "Good" Death," in *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 33.

⁴ Lydia S. Dugdale, "Dying, a Lost Art," in *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 3.

⁵ Lydia S. Dugdale, "Dying, a Lost Art," in *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 3-7.

⁶ Lydia S. Dugdale, "Dying, a Lost Art," in *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 7.

⁷ Lydia S. Dugdale, "Dying, a Lost Art," in *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 3.

⁸ The Hasting Center, *The Goals of Medicine: Setting New Priorities* (The Hasting Center, 1996), 23.

⁹ Atul Gawande, *Being Mortal: Medicine and What Matter in the End* (New York: Metropolitan Books, 2014), 259.

The complex relationship between p4 medicine and pharmaceutical innovation

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The concept of *P4 medicine* (predictive, preventive, personalised and participatory) represents a holistic rather than reductionist approach to therapeutic treatment but raises many questions. Is there a role for Big Pharma in P4 medicine? The vast majority of characteristics that we share and make us recognisably human enable reliable generalisations to be made. These generalisations are an essential part of everyday life and take the form of (1) in most cases, (2) in some cases or (3) rarely. All medical generalisations and their relevance to individual treatments may be more or less well-grounded but are nevertheless subject to unavoidable therapeutic limitations. This is because human beings are unique individuals exhibiting a vast and complex array of genetic and biochemical characteristics that modulate individual aspects of disease, and both beneficial and harmful responses to medication.

From a pharmaceutical perspective, it is the "personalised" element of P4 medicine that is the most relevant. The vast majority of pharmaceutical medicines developed during the second half of the C20th are dependent on a rather simple but successful reductionist research paradigm. Identify a chemical molecule by computer design or animal modelling that may alleviate the symptoms of a recognised disease or illness and validate with clinical trials. The process is ultimately one of trial and error but can result in new and *relatively* safe and effective medicines for the majority of recipients.

The Center for Translational Molecular Medicine (now a component of *Lygature* in The Netherlands) set out the rationale for an approach to personalised medicine: "Molecular Medicine targets disease where it is caused: at the level of the gene or the gene product in the critical cell. It enables not only earlier and more precise detection of diseases and even predisposition, but also personalized treatments that are more effective, cause fewer side effects, and are more cost-effective due to stratification of specific patient risk and prediction of response to therapy. Molecular Medicine combines fundamental discoveries in the underlying (molecular) biology of health and disease with breakthroughs in medical technology, particularly in the areas of Molecular Diagnostics and Imaging" (2006).

But can the prospect of increasingly precise medication realistically ever be more than aspiration? The paper will explore some of the expectations and limitations of P4 Medicine from a drug development perspective with the primary focus on knowledge extrapolation, and economic factors. What are the epistemological and ontological limitations concerning abstraction from genomic data, genuine opportunities for stratification (other than in very limited circumstances), and the availability of valid biomarkers? Above all,

commercialisation as a driver and return on investment is a major and perhaps crucial consideration for society. Affordability is not simply a matter for the industry but even more so for health care generally. Is it feasible - can we do it - could society afford it?

The responsibility of women at the time of genome editing

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In the near future, the development of genetic engineering techniques will allow modifying the genetic code of future people, both to prevent the occurrence of important diseases and to enhance particular features and capacities. Considering this ability to adjust the future person's genome, it could be worthwhile to conceive an embryo in a test tube rather than sexually. In vitro fertilization could in fact allow genome intervention editing to be more precise, hence safer both for the baby and for the woman. With reproduction in vitro, we could also produce a number of embryos, and, to edit the genome, select the one with the best genetic characteristics. Given these possibilities, women who will in the future want to have a child may feel morally obliged to resort to assisted reproductive techniques. Today, women who choose to leave home are considered bad mothers, as they put at risk not only their own health but also their children's. Tomorrow women who become pregnant through sex may seem irresponsible, because they not only have no qualms about putting into the world the embryo with the best genetic code they could conceive, but also make genome editing interventions on the unborn child much more difficult. We intend to examine whether, with the development of genome editing technology, women will increasingly have moral responsibility to give up sexual reproduction and follow the path that promises the birth of the genetically best embryo conceived and then coming into the world. Our conclusion is that the moral obligation to give up sexual reproduction can be justified on the basis of considerations relating to both the welfare of the person who will come into the world and society's interest in having citizens who are more resistant to certain diseases or with particular genetic predispositions. We will add that, for the same reasons, in the case of genome editing being practiced on the embryo in the woman's body (in vivo), the woman has the responsibility to undergo all those analyses and procedures allowing a framework of the unborn child's genetic code and modifying its genes.

Moral enhancement and human enhancement: better morality for better biotechnologies?

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The aim of the paper is to look on moral enhancement as a possible system part of morality, which regulates biotechnologies. The role of moral enhancement may become as a supplement for biotechnologies development and a way to weaken moral and social risks connected with biotechnologies. Is it possible to support other types of human improvement through biotechnologies, not supporting moral biotechnological upgrade? This question may be reformulated differently: is it possible to develop technologies to improve humans, while maintaining the traditional "rational" or natural morality, based on the principle of reciprocity of human experience and free will? Is it possible to select some areas to be designated as areas not subject to any modification of biotechnologies? For example, we have a moral obligation

to improve humans, so that they could adapt to the environment, but this modification should not affect their metaphysical nature, which lies at the base of the free will.

But because of benefits analysis of permissible boundaries is the main theme of philosophical and ethical support of biotechnological projects. Moral approaches help to draw new lines for new biotechnologies and make new restrictions for their development. But there are such situations, when the supporters of the warnings about the dangers posed by the improvement of people (up to the loss of not only the traditional form of humanity, but also of self-identity at the biological level), and supporters of radical human improvement, which, on the contrary, does not see human being as biological and spiritual that should be retained, are in a period of moral doubt and reflection. Including of moral enhancement as a kind of normative biotechnologies into moral system may make some sense for moral enhancement. (The report is prepared with support of a project funded by RHF, № 15-18-30057).

Ethics of 3D bioprinted human tissues

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3D bioprinted human tissues are quickly becoming a reality as replacements for failing organs or organ parts, or as a means to test new pharmaceuticals or therapies. With these new scientific breakthroughs, and the possibility of new treatments, come some difficult, ethically-charged questions concerning: 1) who should take part in the research responsible for bringing these treatments to market, 2) who should receive the treatments after government regulatory agencies have approved them, and 3) exactly what types of issues or disorders should these treatments be used to combat? It is this third question, and specifically how it relates to children with neurological issues, that will serve as the focus for this presentation.

Each of these questions is likely to arise with regard to a wide variety of medical treatments; yet, because it is a cutting-edge technology with the potential to develop novel treatments, 3D bioprinting brings forth a range of original and potentially enlightening ways to explore and answer these questions. In other words, 3D bioprinting offers a new, unique lens through which to analyse these important ethical questions. The repercussions and potential benefits of novel, invasive, and potentially risky procedures of any kind are heightened when dealing with children, as well as when dealing with procedures that impact neural functioning. By focusing on children who have neural functioning deficits (owing to disease, structural abnormality, or injury), a greater number of ethical questions can be examined, including: 1) who should receive treatments and 2) what should the desired outcome of these treatments be?

Although 3D bioprinting, and especially 3D bioprinting of neural tissue, is still in its infancy, it may lead to cures for poorly managed or previously incurable neurological disorders. It may also provide a way to increase the cognitive capabilities of children (at least in certain contexts) beyond what we currently consider to be a 'normal' level of functioning for a healthy, average child. This raises a series of philosophically intriguing questions. Might such enhancement be desirable? Or should it be avoided altogether? Is the prospect of cognitive enhancement only acceptable if the enhancement is inextricably linked to the cure or improvement of the original disease or disability? Could enhancement be a new type of evolution based on intelligent (and human) design, which we should all embrace? These are difficult questions that will be considered in this presentation. Arguments backed by theories of transhumanism and liberal eugenics will be included to suggest that at least some cognitive enhancement in children beyond a species-normal level of functioning could be beneficial both to individuals and to society as a whole.

Sex, Drugs, and how to Deal with Criticism: The Case of Flibanserin

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In August 2015, the FDA approved flibanserin as a treatment for Hypoactive Sexual Desire Disorder (HSDD) in premenopausal women. We argue that this decision and the process leading towards it fail with regard to a principle of “uptake of criticism” (Longino 2002), which expresses the idea that engaging with criticism is a means against blind spots and bias. Firstly, this principle requires opportunities to express and discuss different opinions; secondly, such criticisms also need to be engaged with if the discourse is to promote the trustworthiness of science. Already in 2009, Boehringer-Ingelheim applied for an FDA approval of flibanserin to treat HSDD, but got rejected. After this, Sprout Pharmaceuticals purchased the right to the drug. The second try at approval was made in 2013; again, it failed. Sprout’s 2015 re-application was finally successful. We argue that this reevaluation was not, however, justified by the third application properly addressing (let alone overcoming) the methodological issues and moderate results that had led to rejections earlier. For example, the entry criteria for the trials were very restrictive, excluding women in homosexual relationships or with common comorbidities. In its rejection of the 2013 application, the FDA had therefore asked for an additional efficacy trial with less strict entry criteria – which the re-application did not provide. Moreover, during the application process, the diagnosis of HSDD was actually deleted from the DSM and replaced by a new category of FSIAD (Female Sexual Interest/Arousal Disorder). The grounds for this action were the vague criteria, questionable rationale, and potential over-inclusiveness of HSDD. The respective changes in the official nosology were neither properly addressed by Sprout’s nor the FDA, yet are highly relevant with regard to the study populations of the former trials. Despite all this, the FDA approved flibanserin 2015. Patient advocacy potentially had impact on the decision. Both the 2010 rejection and the 2015 approval were preceded by FDA Advisory Committee Hearings, which invited the public to contribute viewpoints. In 2015, this opportunity was seized by members of the “Even-the-Score” campaign, which portrayed the matter as one of gender equality. Not only was this campaign largely financed by Sprout Pharmaceuticals, it was also staffed by experts that have been involved in the hunt for a female Viagra from its beginnings in the 1990s. We diagnose multiple violations of the principle of “uptake of criticism” that took place in the process. Firstly, the drug manufacturer and associated researchers failed to respond to critical remarks challenging the methods used for establishing the prevalence of HSDD and the efficacy of flibanserin. Secondly, the FDA did not require that its recommendations would actually be followed or at least responded to. In addition, the public hearings were exploited by a group tightly associated with the manufacturer, and, consequently, failed at serving the purpose of offering a forum for genuine critical interaction. In order to better fulfill the principle of the uptake of criticism, we propose a number of institutional measures.

Ethical guidelines for a population-based health monitoring based on emerging technologies

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Today, we witnessed the emergence of a new phenomenon in science and technology: the convergence of at least four main technologies and scientific disciplines, the so-called NBIC -

nano - and biotechnology, information and communication technology, and cognitive sciences. Singly, each of them has a large potential to change society and mankind, but combined they represent a more powerful source for even bigger changes.

This technological convergence reinforces the development of these different technologies creating new application domains by their combination, with an important influence in the health sciences, and in particular on the feasibility of detecting an existing biological condition predisposing to a pathology, or identifying susceptible individuals in the population. In this developing field, we can distinguish between three different pathways:

- i) molecular biology tests for predicting the development of a given disease;
- ii) record-linkage between BIG DATA archives of various origins (commercial, economic, institutional, social networks, etc.) resulting in the definition of subsets of the population to consider at higher risk of developing a disease; and
- iii) record linkage between electronic administrative health archives, which could be processed using disease-specific algorithms to identify individuals with disease amidst a general population.

We present the results of the project “Ethics and Emerging Technologies: a Population-based Health Monitoring Project”: an interdisciplinary research group that seeks to identify and address those ethical issues related to the integrated use of new technologies (NIBC) in the healthcare field so to achieve a global management of the overall health of the individuals within the community and their environment.

Our objective is to draw up ethical guidelines for managing the potential and critical issues raised by the convergence of the study of the results coming from epidemiological data and health records, genetics data, nanotechnology, and neuroscience concerning the individuals belong to a region. We need to deal with: the value of data, privacy, different consent forms and modality, priorities and urgent health needs of the population, prevention campaigns, therapeutic and personalized approaches, intervention planning and resource allocation

The BCI application by DOC patients in-between claim rights and liberty rights

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Recent neuroimaging findings have brought paradigmatic results where, with certainty, the decades-presumed generalisation of “hopelessness” related to patients with Disorder of Consciousness (DOC) are slowly vanishing from the scientific and bioethical dictionary. These recent studies have presented the inadequacy of the current bedside tools for assessing the level of awareness and consciousness, demonstrating the worrisome high percentage of misdiagnosis between the vegetative state (VS), recently known as unresponsive wakefulness syndrome (UWS), and minimally conscious state (MCS). Furthermore, not only was the discovering of the misdiagnosis revolutionary, but so too was the establishment of limited communication with patients in MCS. However, the use of neuroimaging techniques (such as PET, fMRI) would encounter some difficulties in application such as high costs, being inaccessible to everyone, and not working in every case. Another more adequate approach in the form of Brain-Computer Interfaces shows great potential, specifically qEEG, and demonstrated much greater sensitivity 90-95% and higher specificity 80-95% in detection of consciousness comparing to neuroimaging techniques. The high rate of misdiagnosis represents an ethical issue, which might lead to the patient emotionally suffering from lack of personal attention or demanding different kinds of pain alleviation by the palliative care process due to the poor diagnosis and prognosis and as a consequence leading to the termination of life-sustaining care. Some authors encouraging the old praxis in front of DOC

ask themselves: even when some patients regain consciousness without the ability to communicate, would it be the real goal of the treatment? Considering that such state is even worse than being in UWS, does not this kind of life deserve to be terminated? These and other considerations lay on the ableism prejudices, where third person values are involved. Despite such considerations in front of these patients, the majority would agree that DOC patients deserve better and accurate diagnosis, but the scientific community has become aware that diagnosis and prognostication among these patients is veiled with uncertainty. While these transient states between UWS and MCS can take longer than one year the questions emerges from these findings, what are we obliged to do in front of them? Are we obliged to extend the period of waiting for these patients to regain some cover consciousness? Do these patients with cover consciousness need to be engaged, and how much, in the treatment decision-making? All these questions and much more have been posed recently by scientists and ethicists to themselves. I would argue that the distinction between claim rights and liberty rights would be essential to answer these questions properly. Where the right on accurate diagnosis, on recovery, on adequate care, and especially to be involved, if capable, in decision making belongs not to the liberty rights but to the claim rights which entail certain duties and responsibilities from physicians, healthcare staff, social insurances, and above all society. For establishing the above-mentioned rights the development and application of BCI systems might be a reinforcement of the claim rights of these persons. Therefore, the question of DOC patients exceeds the local clinical setting and becomes a question of humanitarian solidarity in front of the most vulnerable.

Ethical, legal and cross-cultural issues regarding umbilical cord bio banking in Africa: Implications for gene therapy of disorders prevalent in populations of African origin

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Recent advances in regenerative medicine and tissue transplantation have highlighted the importance of umbilical cord blood (UCB) as an alternative source of haematopoietic stem cells, which is life-saving for many clinical disorders including genetically acquired disorders prevalent in populations of African origin. There appears to be existing cultural awareness about UCB and placental tissue in various cultures that attribute material and spiritual properties to these human tissues, which may need to be updated with scientific research to enable new modalities of UCB harvesting and storage for stem-cell derived gene therapy. This paper examines cultural issues surrounding UCB bio-banking, and attempts to reconcile traditionally held values with modern ethical principles. Tensions between traditional and modern concepts of the self, informed consent and privacy will be assessed to identify opportunities for creating cord blood banks (CBBs) in Africa. A case is made for the opportunity provided by stem cell research and gene therapy to effectively address genetic disorders affecting African peoples and their descendants throughout the world, including genetic disorders like sickle cell disease (SCD), thalassemia and other genetically acquired disorders. Ultimately, the paper explores practical policy options for designing appropriate legal and regulatory instruments to promote broad participation while taking into account traditional cultural practices for UCB storage and disposal. UCB banking presents several ethical and regulatory challenges regarding its procurement and use, especially in African countries, where majority of the population are vulnerable and prone to exploitation. Currently only privately funded CBBs are available in some African countries like South Africa. Furthermore, the local regulatory framework for biobanks is still rudimentary with no clear guidelines. The current situation raises ethical questions about informed consent,

ownership of human tissues including UCB, and the cost-effectiveness of harvesting and storage of UCB for universal use. There are also concerns regarding undue influence on donors, and issues of distributive justice regarding the fact that UCB, which could be easily obtained, may become a resource unfairly restricted and available only to the wealthy, who can afford to pay for privately funded CBB. In view of the fact that UCB has become a valuable, non-invasive source of stem cells for regenerative therapy, establishment of a publicly funded CBBs in Africa would vastly improve the availability of haematopoietic stem cells for research and therapeutic purposes. This paper will address some ethical, legal and cultural perceptions regarding UCB bio-banking in African communities. Taking education-orientated community-based approach to UCB banking will ensure the necessary genetic diversity and affinity of donors, which could enable a Pan-African, public internationally funded CBB facility, valuable for Africans living within Africa and the diaspora.

Uterus transplantation - new procedure, new problems

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In 2014, the first child from a mother with transplanted uterus was born. Since then, a few other children have come into this world in similar circumstances. Uterus transplants give women with UFI (uterine factor infertility) the ability to become pregnant, but it remains an experimental treatment and may have many ethical and legal implications.

The advanced medicine which make uterus transplant possible can satisfy the very strong desire to have genetically related children and allows the experience of pregnancy for women whose other alternatives for being a parent are gestational surrogacy and adoption. That wish is not without importance as it is a part of a vision of a good and satisfying life. The alternatives do not meet the most desired conditions, and moreover, surrogacy is still illegal or unregulated in many countries, and remains a controversial issue in contemporary ethical and legal debates on human reproduction.

The uterus is a unique organ in female's body due to its reproductive function. Assessing the possibility of a uterus transplant on the criteria of existing standards of organ transplantation ethics would be to underestimate the complexity of the problem. A uterus transplant is a non-saving-life treatment, but still has great influence on the quality of life for prospective mother. There is also a specific goal to achieve: a child. The fetus or future baby becomes another party in the whole procedure, apart from the donor (who may be deceased or living) and the recipient. For all three the procedure of uterus transplantation involves considerable risks to be taken into account.

In my presentation I will make an attempt to find and characterize the main problematic issues associated with the uterus transplant. I will also try to analyze ethical arguments that emerge in the growing debate about the experiments that have been made in the recent years in this field of medicine. The emphasis will be placed on the question of ways in which uterus transplantation is different from or similar to other forms of organ transplantation.

The ethical impact of enhancement goals in an evolutionary perspective

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This paper departs from a long-term evolutionary perspective in which the future evolution of humankind is proposed to evolve in the direction of the phylogenetic enhancement of the hominisation process within the framework of a further progressing modernisation, ultimately resulting in the evolution of transhuman and posthuman stages in the hominine phyletic lineage.

Considering that both the traditional religious ideologies and the current secular ideologies are partly inadequate to deal with the quantitative and qualitative population challenges of humankind in modernity and to safely guide the human species through new subsequent stages of biological evolution and cultural development, the authors argue that evolutionary ethics can, in the context of a further progressing modernisation, provide the framework for reflecting upon the future ethical trajectory the human species ought to take.

The evolutionary rationale for ethical choices is that the past direction in human evolution is characterised by a process of increasing evolutionary complexity that has resulted in an enlarged potential to understand the world, to adapt better to environmental diversity and challenges, to master our own biology and our environment, to increase our survivability and longevity, to satisfy our needs and desires, and to reach higher levels of quality of life, welfare and well-being. The extrapolation of this process will enable a further increase in the human-specific potentials and, through them, further enhance the well-being of humans. It is assumed that an enhanced hominin stage beyond the present *Homo sapiens sapiens* stage might put future humankind into a better position to cope with the cosmic, biological and sociocultural challenges, which will confront it in the future.

The future progressive hominisation goal will require phenomic and genomic enhancement interventions to further increase human adaptive capabilities to higher levels of modernity.

It can be expected that increasing the genetic endowment and phenotypic appearance of the population composition will ethically and politically be strongly opposed in many quarters. Hence, considerable ethical and scientific efforts will have made to disseminate these ideas and convince ethicists, religious institutions and especially policy makers about the utility of human enhancement goals.

Making Life Extension Possible: an Ethical Duty?

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The right to Health is the right to a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO). A longer and healthier life is enjoyed by the citizens who chose to benefit from it. This evolution is also positive for the whole society. A largely delayed senescence has positive ethical, economic and sociological consequences. It is better for a sustainable environment, for a peaceful society, for the level of well-being in the community and for the general level of wealth.

However, the most important reason to do research through gene editing (and through other means) for life extension is not the advantages to the people or to the community. It is the fact that:

- The right to live is the most fundamental right in terms of ethics and human rights
- Senescence is nowadays the first cause of death in the world

- And to be able to avoid death from senescence is a possible future and this future is far closer if medical research against senescence becomes a priority.

Some people will argue that life extension is unnatural or against religious principles. The fact that ethical principles are often against "natural" principles and that religious principles have to be examined with due consideration to new possibilities that were not thinkable even one century ago will be approached. We also need to understand that so many things that are "natural" are not "good" for us and also that in so many ways we do not just accept what is "natural".

The question of the ethical necessity of health research funding will be approached. How could states and international organizations promote and subsidize life extension? Taking into consideration, medical progress and the possibility of accelerating it, we can consider the right to life and the right to health as defined by ethical norms, in national laws, national constitutions and international treaties under a new light. In other words, we could envisage scientific research for a longer life as a general moral obligation. If life extension appears to be possible with scientific research, this research could be considered a new form of a Duty to rescue. In most ethical systems, helping other people in need is an ethical duty. In many countries, the criminal law makes a legal requirement for citizens to assist people who could die or be seriously injured if not helped. Is it possible to imagine this obligation on a larger scale as a duty to do scientific research for life extension?

Parental exclusivity and third-party contributions to the creation of children

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Apart from exceptional cases in which e.g. grandparents have been awarded visitation rights, parents are allowed to exclude any individual from their children's lives, regardless of the interests of anyone involved. This is the case throughout the Western world. In part, this status quo is meant to allow parents the space needed to discharge their parental responsibilities. Arguably, intervening to regulate parental behaviour in such matters would be a problematic interference into the family, with a potential to harm not only parents but also children themselves.

The entitlement of parents to arbitrarily exclude others from their children's lives can lead to the prevention or loss of connections that may be extremely important for children and others who are not their legal parents. For example, some children who have been conceived following gamete donation express a strong desire to know their donors. In the future, children conceived following mitochondrial transfer might likewise express a desire to meet the egg donor. However, even in legislatures where it is in principle possible for children of gamete donation to identify and reach out to the donors, they might not know that they were donor conceived: because whether they come to know of this is up to their parents. In the case of mitochondrial donation, the explicit effort to minimise the contribution of the egg donor pulls towards not allowing children to value it and identify her. One of the things that makes this possible is the scarcity of ways to even express connections to children independently from their parents. This leads to a framing of such situations in terms of competition to parenthood status: if genetic connections however slight are about parenthood and family, then they are a threat to the legal parents; if they are not, then children cannot have an interest in them.

In this talk, I will look at parental exclusivity in the context of third-party contributions to the creation of children. I will highlight the lack of terminology apt to describe children's

interests and connections outside of the family. I will look at current ambivalence regarding the value of genetic links and resistance to acknowledging children's interests to access their personal history. I will show that the conceptualisation of children as holders of moral status who have interests independent from those of their parents is still underdeveloped. Intervening in families to ensure that children's interests are respected is difficult, and any choice to allow children more agency, especially against their parents' wishes, is fraught with risks of harm. However, not challenging this status quo in any way might not be compatible with current ethical and legal aspirations regarding the moral status of children and the importance of their interests

Digitalization of healthcare from a patient's perspective/through the patient's lens

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The last century our lives have been 'digitalized', with new technologies rapidly becoming an integral part of our lives. It is widely accepted that with their implementation, these technologies have changed the way we live our lives, experience our relationships with others (e.g. Facebook) and our access to knowledge (e.g. just google it!). Within healthcare, the implementation/utilization of new technologies has been widely debated, with a tendency to focus on their expected benefits. It is assumed that the technologies enable the patient to better manage their own help, resulting in an increased empowerment (Eysenbach, 2001).

However, only minor empirical research has investigated how patients experience these technologies, and if they actually feel more empowered through it. This question seems especially relevant for men diagnosed with testicular cancer as 1) this cancer mostly affects young men in their early years, a group that is familiar with technology, and 2) previous research (Ziebland et al., 2004) has noted that this group is using the internet more often than patients with other types of cancer.

With an interdisciplinary research team (ethics, clinical psychology and medical oncology), we are currently conducting a study to grasp the illness-experience of men with testicular cancer. As the aim of this research project is to explore the experiences of these patients, we opt for the Interpretative Phenomenological Analysis (IPA), making use of semi-structured interviews. This enables us to gain a situated, relational, embodied and enactive account/narrative from our participants.

In this presentation, the narrative of the patient will form the base to tackle questions such as: the consequences of the digitalization of healthcare for the patients' experience. Which meaning do patients ascribe to new technologies? Does it lead to a feeling of empowerment? Does the use of technology and the wide access to information through the internet fulfill the need for health information in patients? And what if their questions cannot be answered by technology?

References:

Eysenbach, G (2001). What is e-health? Journal of medical internet research, 3(2), e20.

Ziebland, S., Chapple, A., Dumelow, C. Evans, J., Prinjha, S., & Rozmovits, L. (2004). How the internet affects patients' experience of cancer: A qualitative study. BMJ, 328(7439), 564

Patient data is not the patient's voice: Towards more reciprocal medical ethics

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Advocates of extensive integrated biomedical data persistently emphasise the benefits of collecting and aggregating more genomics and routine patient data to research and public interests, and thus the necessity of reducing the hurdles of informed consent. However, healthcare stakeholders (HCS) may not be sufficiently aware of the ethical risks attached to the rapid development of large patient data sets (health big data) in terms of patient rights, social justice and trust in public institutions.

Based on the material from a qualitative research study interviewing 22 Swiss HCSs (physicians, policy-makers, IRB members) involved in the collection and use of patient data, I identified tension between the legitimacy and utility of collecting and using patient data for research and public interests on the one hand, and the recognition of patient rights and agency, as well as citizens' involvement on the other. Promoting further data sharing on the grounds of research and public interests would run the risk of provoking more distrust towards the healthcare system, and eventually prevent its expected social benefits. Nevertheless, the dominant observation of HCSs' rationalizing data-use from a largely utilitarian perspective might distort the moral evaluation of infringing patient rights for the sake of public interests.

To protect patient rights, I suggest reversing the ethical thinking towards a more patient-centred and reciprocal ethics, contrary to the usual top-down ELSI (ethical, legal and social implications) approach to genomics and big data in healthcare. Brownsword has proposed the formation of mini-constitutions protecting patient rights against disproportionate claims of public interests. This human rights approach reverses the direction of present-day ethical approaches, by starting with defining what constitutes the inalienable core of patient rights before creating the rules for appropriate data sharing. Ricœur has recognised at the deontological level the threat of "objectifying" the human body following the mixing of the therapeutic project and the epistemic project of biomedical research, or in other words the tension between considering the patient as a person, and the protection of public health. For him, it is necessary to maintain reciprocity in the trust agreement, avoiding patient's regression to dependence on the HCSs.

I argue that these two judicial and ethical reflections reconcile patient dignity and public interests in relation to patient data, and could represent the normative basis for justifying a more participative justice in order to change HCSs' perspective and to involve patients and citizens in the governance of health big data.

On moral enhancement in the overmedicated society

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Many philosophers agree that making morally correct decisions is critical for the well-being and even survival of humankind. The relationship between cognitive, motivational, emotional and moral aspects is extremely complex. Values, attitudes, knowledge and feelings that are involved in creating moral decisions are closely interconnected. Therefore, it is difficult to distinguish how much, in our moral reasoning we rely on rational discourse, and how much we depend on our emotional and impulsive reactions or instincts. Irrespective of which moral theory one advocates, it is undeniable that there is no moral reasoning without a biological substrate, the brain. However, it is unknown to what extent the brain functioning is predetermined by genetics and neurodevelopment, or shaped by education and social factors,

as well as with other environmental influences, such as nutrition, medication, physical injury or trauma. Our brain has been molded by every experience during our life-time, as well as with our own inner self.

The progress in neuroscience, neuroimaging and neuropharmacology are allowing us not only to better understand, but also to influence our brain. By treating some health problems, medications often interfere with our everyday behavior, and might also affect our decision-making and moral judgment. On the other hand, increased understanding of neurobiology opens up space for possible targeted moral enhancement. The intriguing question is what are the attributes that a “morally enhanced man” should possess? This lecture aims to present the most common and widespread medications used today and to discuss their potential effect on moral reasoning.

The human body in the age of mechanical reproduction: 3D bioprinting for purposes “beyond therapy”

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The new technology of 3D bioprinting, an application of 3D printing used to create replacement bones, biological tissue, and even full-fledged organs, is increasingly capturing the attention of ethicists. Among other things, it promises to help remedy the current shortage of organs for donation, and to facilitate drug discovery, helping to reduce the need for animal testing. While such prospects are virtually universally applauded (even though they do require further reflection on issues relating to safety and challenges for clinical trial paradigms), 3D bioprinting has also been repeatedly cited as a source of ethical concern when it comes to its possible non-therapeutic applications. Those that have been suggested include (a) professional athletes using the technology to enhance their bodies and boost their athletic performance; (b) “body hackers” or artists experimenting with the creation of artificial tissue and body parts; (c) the army seeking to build enhanced soldiers; (d) the iterated replacement of organs in order to extend the human lifespan; and (e) the use of the technology, for instance by “garage” scientists, to create and disseminate dangerous pathogens (voluntarily or not).

In this paper, we consider these prospective uses of 3D bioprinting “beyond therapy” and highlight the risk of fuelling hype when discussing the ethical concerns that they raise. For one thing, ethical analyses of these prospective uses sometimes take for granted developments that are still wholly speculative, and tend to minimize some of the technical challenges involved. For another thing, even assuming that such developments will materialize, it is unclear that they would raise new ethical issues – compared to technologies that have already been discussed in the applied ethics literature – that would justify the introduction of separate regulations. That said, we do note that some prospective ways of using bioprinted body parts would seem to challenge the traditional dichotomy between treatment and enhancement: the first people to get enhanced through 3D bioprinting might thus be seeking to remedy a pathology or disability. Furthermore, we argue that the familiar ethical concerns – safety aside – that might be raised in relation to uses of 3D bioprinting beyond therapy remain of limited force in light of the various potential benefits of such uses. We conclude that, for the time being, ethicists should focus on regulatory issues surrounding near-term, medical uses of 3D bioprinting, while keeping its expected benefits in mind and continuing to monitor the latest developments of the technology, in order to avoid overlooking any future breakthroughs that might present unforeseen regulatory challenges.

Novel therapeutics: advanced prosthetics — an ethical dilemma

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Background: The technology behind prosthetics and aids has advanced significantly in the last 50 years. As a result of this development, prosthetics are now lighter, more controllable, more realistic/stylish, easier to wear, and can even be driven by neurological stimulus from the wearers' own body; while aids have become more comfortable, have greater usability, and perform a broader selection of functions. These advances in technological seem to further reduce the experience of disability for certain individuals, and are at first, immediately intuitively positive.

On further investigation, however, advances in novel therapeutics embolden worries over 'normalisation' as technology becomes more adaptive. Modern day prosthetic limbs, for instance, are becoming as little of an intrusion as reading glasses or contact lenses and are beginning to command the same type of acceptance. Yet, the carte blanche appropriateness of these therapeutics is ethically less clear — especially with respect to the distinction between congenital and acquired disability.

Deference to the hegemonic models of disability (namely, the social and medical models) perpetuates flawed models of disability, and results in inaccurate and potentially improper conclusions. Furthermore, these hegemonic models are of little help in identifying the boundaries of normalisation: the medical model actively promotes normalisation through the use of prosthetics and aids, and the social model repudiates normalisation at all (which is problematic for persons who acquire an impairment and would like to have their functionality returned). The Picture Theory of Disability (PTD), however, offers clearer indication of when novel therapeutics are appropriate and when they are not.

Results: The use of prosthetics with certain impairments — especially at developing ages — can be counter productive, i.e. the use of prosthetics may generate less adaptability and functionality if encouraged during developmental stages; the use of prosthetics to return function to those who acquire disabilities are almost always ameliorative. The PTD is able to show when and how prosthetics and/or aids would reduce the experience of disability and when and how they are beneficial. The PTD does this through careful examination of the lived experience together with a visualisation of the experience itself. This theory thus improves upon the responses from the medical and social models which are found wanting in this arena.

Conclusions: Common sense intuitions about developing technology — especially in prosthetics and certain aids — seem to approbate their use. However, these intuitions become trained when we draw the distinction between acquired and congenital impairments. The medical and the social models of disability offer little in the way of indicative guidance, as one actively promotes normalisation and the other condemns the need to conform to social norms. The Picture Theory of Disability stands as a better guide to resolving when and where these technologies are more appropriate.

How challenging is an ethical framework for biobanks in practise?

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Biobanks are organized collections of biological material of human origin and information related to this material. There are diverse types of biobanks ranging from small collections of residual specimens collected during routine clinical care for therapeutic purposes to large

population based biobanks. The aim of biobanks is to provide biomedical research with high quality specimens usually collected and processed under standardized conditions together with associated data about their donors (e.g. clinical information, lifestyle information, genetic data, etc.). This way biobanks contribute to research, which is expected to result in new diagnostic methods and more effective treatment.

Due to the recent emergence of biobanks ethical framework of their activities is still being discussed. The core question is how to balance the individual's rights and the benefit for society from the perspective of common good. Particular attention is given to form of applicable consent, which differs considerably from the traditional informed consent proposed by the Helsinki Declaration. In biobank the consent involves research whose future specific aims cannot be clearly identified at moment of consent¹. The donors of biological material consent at the same time to banking and use of specimens, to processing of personal data, to waiver of any (real or notional) rights of future control over long-term use of samples and data².

Under such conditions of specimens donation biobanks have a duty to protect the privacy of donors and security of stored data by avoiding their improper use. Transparent conditions for access and use of specimens and data is therefore one of requirements for protection of the interests and rights of donors. One of the proposed ways to benefit the donors is return of research results mainly from genetic research, which can reveal some of the future health risks for donors. Current opinions differ in this regard taking into account practical but also ethical consideration like the "right not to know".

With recent emergence of big data primarily from genomic projects and ongoing international research projects the concept of biobanks harmonization is being promoted. Harmonization of biobanks governance would allow share specimens and data internationally and make the investigations more robust, targeted and effective. Nevertheless the biobanks are working in different countries within different legal frames and especially specific social and cultural background. This paper will present the experience with implementation of ethical framework in practice through semi-structured interviews with the staff of recently built research biobanks in Czech Republic.

¹) Caenazzo, L., Tozzo, P. Pegoraro, R. (2013): Biobanking research on oncological residual material: a framework between the rights of the individual and the interest of society. BMC Medical Ethics, 14:17.

²) Ascroft, R.E. (2007): Human rights and ethics in genomic research: rethinking the model. Pharmacogenomics 8(7), 391 – 395.

Between 'Entertainment Medicine' and Professionalization of Healthcare: An Interview Study of Belgian Doctors

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Nowadays individuals are offered a plethora of possibilities to self-track and manage their personal health. Self-tracking through mobile and wearable computing has become known as 'the quantified self' (QS) (see e.g. Lupton 2013). QS technologies, which ultimately are small computers that record data, provide the individual with detailed information, including sleeping habits and calories burnt. This knowledge of bodily activities leads to shifted self-understandings (Sharon & Zandbergen 2016).

Classic self-tracking methods provide support to enhance *self-care*. Before the wider dispersal of apps and wearables, self-tracking methods incorporated in self-care relied on rather simple techniques, amongst others the thermometer and bathroom scales. Physicians as well have

been recommending self-tracking, both on the level of self-care (e.g. in diabetes management) and professional care (e.g. cardiac monitoring).

Health apps and devices hold the promise to discover medical problems earlier in the disease process and also serve to coach the self-tracker towards behavioral changes (Piwek et al. 2016). Self-tracking technologies are intended for both 'healthy' people (preventive use) and for patients who already suffer from a medical condition (curative use). In both cases, the data could be shared with a professional healthcare provider.

This study suggests that self-tracking in a private setting will lead to shifting understandings in professional care. In order to attain more insight into these shifts, this paper seeks to lay bare the promises and challenges while staying close to the everyday professional experience of the physician. Our objective is twofold. First, to offer an analysis of how medical doctors evaluate self-tracking methods and of how classic and digital self-tracking methods are incorporated in their daily healthcare practice. To this aim, in-depth interviews with general practitioners (GPs) (n=7) and cardiologists (n=5) have been conducted in Flanders, Belgium. Second, to explore the anticipated shifts that digital self-care will bring about in relation to our findings and those of other studies.

Our research findings show a nuanced understanding of the potentials and pitfalls of different forms of self-tracking. Four major themes arise in our body of data. First, the patient as health manager; second, health obsession (i.e. a concern towards a focused use of self-tracking by healthy people); third, information management; and fourth, the shifting role of the doctor and impact on healthcare organization. The dialogue between our dataset and the existing literature sketches a fine-grained image of digital self-care.

References:

- Lupton, D. (2013). Quantifying the Body: Monitoring and Measuring Health in the Age of mHealth Technologies. *Critical Public Health* 23 (4), pp. 393-403.
- Piwek, L., Ellis, D. A., Andrews, S., et al. (2016). The Rise of Consumer Health Wearables: Promises and Barriers. Lukasz Piwek, *PLoS Med* 13 (2).
- Sharon, T., & Zandbergen, D. (2016). From Data Fetishism to Quantifying Selves: Self-Tracking Practices and the Other Values of Data. *New Media & Society*, online first, <https://doi.org/10.1177/1461444816636090>.

Pharmacological moral enhancement. The case of ADHD

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Moral enhancement has been a hot topic in bioethical debate. While several researches in neurobiology have provided the scientific basis to envisage future pharmacological enhancement of moral decision-making, most debates were about future application of such techniques. However, someone could claim that we're already practicing moral enhancement, for example when physicians prescribe psycho-stimulants to children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). This judgment is warranted to the extent that we can accept two premises. First, the premise that ADHD is not a pathology, but a variation on normal behaviour which is not tolerated according to some social standards; or the premise that ADHD is a social construction at least in part. Second, the premise that a pharmacological intervention that intervenes on cognitive processes is a moral enhancement.

The first conclusion would be that, if we have some reasons to accept that ADHD is in part a social construction, so the use of psycho-stimulant drugs is in some cases a form of cognitive enhancement, which can have significant consequences on moral decision-making and behaviour. Once stated that the use of psycho-stimulant could morally enhancing children, we should evaluate whether it's morally right or acceptable. We can't provide here a

comprehensive evaluation of its status but, granted that psycho-stimulants have not harming side-effects, we claim that their use as enhancer is *prima facie* morally acceptable because they don't limit individuals' "freedom to fall" ("Harris condition") nor their mental freedom ("Butblitz condition").

Health, life extension and successful aging: A philosophical approach

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This presentation aims to provide a detailed analysis and reflection on what is to extend human life with health. On numerous occasions, either from science or from either philosophy, it has admitted that biomedicine, in the medium term, will allow time to prolong our existence without extending the period of decrepitude. However, it is an idea that has not been exposed with the desired precision and rigor.

To do this, I present how we must approach this issue from the knowledge of the latest developments and projects in gerontology. This will provide a strong scientific basis, which will propose a possible scenario within a few imaginable limits. Thus, certain ideas and promises that lack any credibility in the academic community are also deleted.

A parenthesis is necessary at this point: I must explain briefly how could conceptualize the extension of human life in three interconnected levels. I will not go into the discussion of the third level (cybernetic and mind uploading options) considered that possibility has no meaning in this presentation.

My main goal is to define what has been termed as "successful aging" to connect with what has been understood for better health. I also argue that there is a very close link with the idea of "compression of morbidity" (along with other bordering concepts in this topic). You can make a number of parallels between proposals as María Blasco or Eric Juengst to understand from a more comprehensive perspective. In addition, before developing the idea I quote then I try to explain how there are two ways to extend healthy human life: a) from a weak sense; b) from a strong sense. I think that "successful aging" is the best concept that can be applied to the extension of life for different reasons:

- 1) This model includes three spheres that are fundamental in the presentation that I want to defend: a) avoid disease and disability; b) a substantial increase in cognitive and physical function; c) a strong commitment to life. Each of these areas need an explanation detailed in this section. Obviously, it will be discussed, criticized and deepen this model from a current perspective.

- 2) It is the proposal that includes a social aging that is key in my analysis: the importance to maintain activity, productivity or social relations.

- 3) It is possible to connect this idea with others, which have had a great run in the recent history of gerontology: Tithonus error or Gulliver's travels among others. Shed more meaning to be able to justify how not to be added to our life years of dependency or fragility.

Finally, I argue why a moderate life extension this way would be better than life we enjoy today.

Challenging the right not to know: incidental findings, biobanks and clinical screening programmes

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Although the right not to know information about one's own health status has become a recognized normative component of modern health care, it is challenged in the contexts where whole genome sequencing based genetic testing has been used. The mentioned ethical controversies arise in relation to return of incidental findings in the clinical settings and research biobanks. Similar challenges seem to be also very relevant in the debate on ethical issues of participatory, preventive, predictive and personalized medicine (so-called P4 medicine).

This paper presents two examples that have recently raised controversies regarding the right not to know information about one's own health status. The American College of Medical Genetics and Genomics (ACMG) Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing (2013) have been a particularly interesting example of a divergence from established ethical principles of genetic testing and counselling. The ACMG recommended that whenever a lab does whole genome or whole exome sequencing on a patient, it should examine selected 56 "actionable" genes on the list included in the Recommendations and report any clinically significant findings to the ordering physician. What has raised a very strong controversy and departure from prevailing norms was the ACMG position (which was modified a year later) that the test findings should be reported without seeking preferences from the patient and family and without limitation due to the patient's age.

Maximising the efficiency of clinical screening programmes has been another challenge to the right not to know details about one's own health. For example, in some countries 50% risk carriers of heritable cancer syndromes who choose not to know their genetic status still have access to the same screening program as those carrying a proven mutation. This implies inefficient use of health-care resources and also leads to unnecessary medical interventions for non-carriers of the mentioned mutations. It has been argued therefore, that as soon as the scope of the screening programmes widens, the need to use personal genome sequencing data to construct genetic risk models that can distinguish individuals into categories of increased or reduced risk of cancer can become very relevant (Shuurman et al, 2015).

The paper aims at examining the mentioned challenges to the established ethical principles of genetic testing and counselling. It seems that these challenges will reinforce each other as long as biobanks, clinical screening programs and other tools of personalized prevention and prediction will become an integral part of modern health care.

Cognitive enhancement, therapy, education – synonyms or morally distinct?

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The humanism project has always aimed at improving the individual human being; developing the personal strengths and possibilities as far as possible. The traditional means for that are above all education, in early childhood by the parents, later at school and finally autonomously by individual effort. In modern times, knowledge has become far more easily to get, but the old problem to get it into the head is still the same. My question in this paper is if traditional ways to improve our receptiveness like living a balanced life with enough sleep and activity, eating healthy diet, using chemical substances like coffee and alcohol in order to

enhance attention and relaxation are in a relevant way distinct from using new chemical substances and devices (mainly developed in therapeutic context in order to ameliorate pathologic conditions). My argumentation results in the conclusion, in spite of all similarities (J Savulescu, B Schöne-Seifert), that there is a morally relevant distinction between education and chemical or mechanical stimulation. Furthermore, even if the later are highly desirable in therapeutic contexts in order to compensate for a disease or dysfunction, and even if some similar substances are traditionally accepted, these compensatory techniques fulfill NOT the same goal and are not morally equivalent to the humanistic “enhancement” project (MJ Sandel).

Civil liability of a cognitively enhanced surgeon

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The problem of criminal responsibility of an enhanced agent (surgeon, pilot etc.) has played a crucial role in the cognitive enhancement debate since its very beginning. The works of authors such as Nicole Vincent, Reinhard Merkel or Jan Christoph Bublitz provided a comprehensive and complex understanding of this problem, offering valuable legal solutions to many abstract philosophical problems. Now, when much has been said about the criminal law consequences of cognitive enhancement, the continental law doctrines must face the much more ambiguous and mistakable problem of its civil law consequences.

The aim of my speech is to analyse the influence that cognitive enhancement may have on some classical institutions of continental civil law. To make my argument more clear, I will present a case study of a surgeon performing a complicated operation under the influence of 200mg of Modafinil. This example will help me to investigate legal notions such as the duty of care (*Sorgfalt* in German law) regarding an enhanced agent and the proximate cause (*Kausalität*) between the agent’s actions and their consequences. One of the most interesting legal controversies in this area of inquiry seems to me the question whether cognitive enhancement may in fact free an agent from civil liability, proving that he or she has in fact fulfilled the duty of care by absorbing a neuroenhancer and, as a consequence, that he or she cannot be held responsible in terms of civil liability.

I will conclude my presentation with a short presentation of possible civil law answers to the problem of cognitive enhancement. I will put special emphasis to the parallel between cognitive enhancement debate and continental civil law doctrine: in both areas of research we can observe an increasing scepticism towards the notions of autonomy and competence of an autonomous agent. I will argue that this parallel may play a significant role in civil law regulations of cognitive enhancement.

Attitudes of medical students from Malaysia, India and Russia toward human enhancement¹

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The anonymous survey on the attitudes of the second year medical students from Malaysia and India, studying in Russia, and Russian medical students toward human enhancement was carried out at the Pirogov Russian National Research Medical University and at the Kursk State Medical University in 2016-2017. The results of the survey indicate no significant social and cultural differences in relation to prenatal testing, doping in sport and the development of

computer-brain interface systems. Some differences were found with regard to cosmetic surgery. Students from Malaysia often called “fashion and beauty standards” among the reasons forcing the young man to turn to cosmetic surgery (except for medical purposes). Also, a survey showed specifics related to the problem of cognitive enhancement. Ritalin is included in the list of banned drugs and psychotropic substances in Russia. Media is sometimes called it the “cocaine for children”. Also, amphetamine and dexamphetamine are on this list too. Provigil is on the list of narcotic and psychotropic substances, the circulation of which is restricted and strictly controlled. Comparative research has confirmed the effectiveness of the ban. None of the students did mention Ritalin, Adderall or Provigil among the means of cognitive enhancement. It should be noted that there are the offers to buy medicines in foreign online pharmacies. According to the responses, the main way to enhance the performance before tests and examinations is the coffee, strong tea or energy drinks. In addition, the concept of academic doping is not actually used by analogy with sports doping, as a means of unfair competition, but only as a possibility of increasing capacity.

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Incommensurable concepts of health and well-being: mental illness, spirit possession and female Muslims in Scotland.

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This paper reports the results of an empirical project relating to mental health in the Scottish female Muslim community. The results, which are of bioethical interest in themselves, are used as a case study to illustrate how apparently theoretical bioethical problems may be resolved in practice. The much-discussed philosophical problem of engaging with groups that have apparently incommensurable conceptual schemes, or ways of looking at the world, is addressed. What does one do when the views one encounters seem to be: non-revisable; irrational; likely to lead to harm? These questions are discussed in light of the tension between Western biomedicine and foundational Muslim religious beliefs in possession by spirits, or ‘jinn’, and other spiritual phenomena).

A significant conclusion from this research was:

- There were reports of increased discussion on help-lines amongst Muslim women in Glasgow about mental health, jinn and possession.
- The women often referred to jinn as causes of mental ill-health.
- Muslim women in Scotland are twice as likely as the rest of the population to experience compulsory treatment for psychotic disorders.
- On the face of it this constituted a situation where different conceptual schemes relating to mental ill-health were clashing, which would pose difficult questions in terms of policy recommendations to increase the uptake of mental health services.
- When given the opportunity to speak freely in focus groups, the women very quickly downgraded the importance of ‘spiritual’ causes of mental ill-health and focussed on more familiar, but still sensitive and controversial, explanations for mental ill-health and its apparent high prevalence in their community.
- Mental ill-health was discussed by the participants in terms of psycho-social phenomena such as the pressures on women in marriage, and the Muslim community more generally.
- In other words, whilst adhering to the Muslim doctrine of the existence of jinn, and assenting to a theoretical idea that they could be the cause of some mental-illness in

Muslim women, a majority of the participants argued that the main reasons why many Muslim women become depressed, or worse, is because of their family lives, and the personal and social expectations this brings.

- In this sense the prima facie tension between spiritual and medical explanations dissolves into sensitive discussion of real but more prosaic problems.

Enactments of Infertility in the Emergence of a New Reproductive Technology An exploration of different actors' accounts of uterus transplantation

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Infertility is a complex and sometimes contested concept. While clinically often defined as the 'the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse' (Zegers-Hochschild et al., 2009:2686) infertility is at the same time caught up in a range of sociocultural beliefs, expectations and norms. Addressing these complexities scholars in social sciences and humanities with an interest in meanings of infertility have, for example, problematized the conflation of a biological incapacity to conceive and involuntary childlessness which can be found in medical as well as media discourses. In parallel, the relational and ethical dimensions of the rapid development of assisted reproductive technologies (ARTs) – which has made them a 'normal' part of individuals' lives across the globe – has been a central interest in such scholarship.

Against this backdrop, this paper engages with the emergence of uterus transplantation (UTx) in the Swedish context. Targeting women with absolute uterine factor infertility (AUI), meaning that the uterus is absent or incapable of carrying a pregnancy, UTx has been described as 'the last frontier' for infertility research to conquer (Brännström et al. 2012). Since 1999 researchers at Sahlgrenska University Hospital, Sweden, have embarked upon this mission by investigating the possibilities of transplanting uteri and in 2014 the first child ever was born as a result of the treatment. As of today five more children has been delivered by transplant recipients in the trial. While the Swedish team so far only has included live donors, who moreover have been related to or friends of the recipients, trials involving deceased donors have been initiated in, for example, USA, China and France.

Through an exploration of different actors' accounts of uterus transplantation this paper examines how infertility becomes enacted in the emergence of this innovation. By zooming in on discursive slippages between infertility and involuntary childlessness it aims to tease out some ethical concerns that so not have been highlighted in academic and public debates. Specifically, it addresses how certain contextualizations may contribute to broaden the ethical discussion around this innovation and, in doing so, it seeks to connect problematizations of the concept of infertility to the more general ethical discussions around the aims of and need for innovations in the field of ART.

The effect of online interruption in patient-doctor encounter on patient perceived service quality

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The phenomenon of online interruption has sparked scholars' interest in the 21st century. The current study focuses on the effects of online interruption on patient service quality perception. The study explores (a) whether and to what extent patients perceive doctor's usage

of new media devices, during their visit to the clinic, as an interruption; (b) whether and to what extent patients perceive this interruption as legitimate and justified, and (c) potential effects of these attitudes as mediators of the perceived service quality. New media usage among doctors during patient visits is becoming common in recent years. One example is mobile phones usage patterns in everyday life including the workplace. This mass usage might encompass some challenges for organizations, such as work interruption.

Empirical studies on interruption have attempted to identify the scope of interruption and its impact on task performance. In healthcare setting, findings indicate that interruptions are frequently associated positively with errors. However, with regard to patient outcomes, the effect on patient perceptions of the service delivery process is not conclusive, although there is some evidence that increased frequency of interruptions in doctor-patient communication is associated with less favored perceptions of the visit. The interaction between patient and doctors is an integral part of the service process. While a patient feels that the interaction is being interrupted by non-legitimate interruptions, he will tend to perceive the service process as not meeting his needs and expectations and, in turn, might affect his attitudes, behavior and decisions. To explore these questions, we utilized a survey of 500 patients. Data were gathered using online panel data collection, with panel participants representing the Israeli population through stratified sampling (N=500, maximum sample error 4.5%). Preliminary findings will be presented.

How technology constructs values: slippery slopes, crowbars, fascination, evasion, and biases

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Technology has changed and continues to change human life like few other factors. Nowhere is that so visible as in health care, where technology not only has come to treat disease and save lives, but also to define life and death, health and disease, and human evolution. This development has urged the question of how technology relates to human values. Is there a technological or a social determinism – or is there a reciprocal relationship between technology and human values? In this presentation I will use some examples from the implementation of emerging health technologies to investigate some processes that can shed light on this question. In particular, I will scrutinize the slippery slope effect, the crowbar approach, human fascination, the value-evasion effect, and some core cognitive biases. My argument is that these effects support the impression that technology constructs values, but that they do not entail the evasion of responsibility. On the contrary, “the technological construction of values” promotes ethical counteracts.

You say 'Enhancement', but I say 'Enhancement'... Let's call the whole thing off

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The literature on the ethics of enhancement technology is growing rapidly, and every new technological development that can be used for enhancement purposes generates a new spike of productivity in the ethics literature.

In this talk I will argue that the ethical enhancement debate suffers from a fundamental problem. The problem is that there is no agreement about what changes in human beings that

should count as enhancements. This leads to participants in the debate talking at cross purposes and provides a basis for easy elision.

Even if we accept that an enhancement must be an improvement we still need to settle:

1. Who or what has to be improved?
2. What is the baseline against which to judge improvement?
3. Who should decide whether an improvement has occurred?

In the talk I will briefly outline all three questions and provide examples from the literature.

The analysis will show that there is no univocal concept of ‘enhancement’ and that authors need to specify which enhancement concept they are basing their argument on.

Timely manners – some epistemological issues in translational medicine

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One philosophically neglected aspect of current practice in medicine is the promise of speeding up of the research and development process, most explicitly present in translational medicine (see Zhang *et al.* 2014: 465). Biomedical research, including both the development of drugs and therapeutic practices, is especially dedicated to time-sensitive outcomes. In recent years, translational medicine is an emerging approach supposed to bridge the gaps between laboratory, clinics, guidelines, practices, prevention, and finally, health politics. The idea is to make research more end-users centred, translating it into clinical practice and health politics in a more productive and patient-sensitive way, while maintaining rigour on the safety part.

I focus on three time-related issues in current translational medicine: (1) unintegrated strategies in early drug discovery (2) translational time lags and problems with their measurement, and (3) time-insensitivity in measuring the effectiveness of medical interventions. I suggest that *synchronicity* is the key feature of a desirable “speedy” or “time-sensitive” translation.

(1) Methods in early drug discovery are based broadly on either the interventive complexity or the systems complexity, where each has considerable success but their merging seems to be a matter of coincidence or a lucky guess (see Adam 2011). This kind of shortcoming cannot provide for a reasonable speeding up of the process, unless in terms of optimizing the chances for coincidences, lucky on both effectiveness and safety.

(2) Measuring translational lags between different translations along the process (from basic to clinical research, from clinical to practice and guidelines, etc.) has been attempted but has seemed to fail in its promise to be informative to the stakeholders and decision makers because of different methodologies used in measuring, ultimately, different things (see Morris *et al.* 2011). Unified models for measuring translational lags and transparent endpoints of the translations might help elucidate the optimal practices.

(3) Finally, measuring the effectiveness of medical interventions is another highly time-sensitive practice, since not every condition has the same time span of development, remission, and possible relapse. The same holds for testing for safety and efficacy, and monitoring for side effects in drugs (see Stegenga 2015). Time-insensitive instruments and methods can contribute to an overestimation of the effectiveness of medical interventions.

To exemplify these problems I analyse a paradigmatic example of translational research, the research on adrenals, which eventually led to discovery, synthesis, and therapeutic application of cortisone. Though it took place before the formalization of translational procedures, it is important to highlight what is so paradigmatic about this case and how it relates to current

translational practice. I argue that the efforts to tactically speed up the development of new drugs and therapies have only limited success, unless speeding means synchronising.

References

- Adam, M. 2011. "Multi-Level Complexities in Technological Development: Competing Strategies for Drug Discovery", in Carrier, M., Nordmann A. (eds) *Science in the Context of Application*. Springer: 67-83.
- Morris, Z. S., Wooding, S., Grant, J. 2011. "The answer is 17 years, what is the question: understanding time lags in translational research". *Journal of the Royal Society of Medicine* 104: 510-520.
- Stegenga, J. 2015. "Measuring effectiveness", *Studies in History and Philosophy of Biological and Biomedical Sciences*
- Zhang, Y., Diao, T., Wang, L. 2014. "Quantitative Evaluation of Translational Medicine Based on Scientometric Analysis and Information Extraction". *Clinical and Translational Science* 7(6): 465-469.

Human-animal chimera as source of 'human' organs – an ethical discussion¹

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World-wide there is a shortage of organs for transplantation to patients with organ insufficiency. One way to try to solve this is by growing human organs in human-animal chimera. This is pursued by injecting human Pluripotent stem cells (PSC) into early embryos of guest animals, most likely pigs that have undergone several genetic modifications to enable the growth of 'safe' organs from the human cells.²

The availability of more organs for patients is medically and ethically desirable. However, this approach also raises serious ethical issues. If this approach will be technically realizable at all, from a consequentialist perspective the safety of those organs is an issue, especially whether the transfer of potential dangerous viral sequences from the guest animal to the patient can be ruled out. The argument put forward by some authors³ that it violates human dignity will be discussed. Furthermore, it will be attempted to elucidate the (emotional) objections that, according to research, many people experience when confronted with this kind of research. Relatively new research links emotionality with value orientations.⁴ These lines of reasoning lead to discussing and critiquing the 'naturalistic fallacy' (NF). It will be argued that the NF is rooted in a specific philosophical tradition and that from a different philosophical perspective normativity does not just come into play when people attribute it to things of events, but can, in some way, be recognized in reality. In this latter approach the distinction between humans and animals is arguably morally relevant and could well be a reason why crossing of species borders is at least one reason why people experience disgust towards these chimera. This argument will be supported by a hermeneutical approach to philosophy of technology, using among others Martin Heidegger and Avraham Heschel. These discourses build an argument for so-called 'soft values', referring to experiences of a life-affirming order and safety in culture, that in addition to the risks, argue why the introduction of this technology, if done at all, should be accompanied by careful vigilance of its safety and deliberation about its broader effects on culture. Furthermore, it should be compared with other approaches, notably in-vitro cultivation of (mini-)organs from human PSC, to reach the same goal (subsidiarity).

¹ This paper is based on a requested advice to the Dutch Ministry of Health (February-April 2017)

² Wu J, Platero-Luengo A, Sakurai M, Juan Carlos Izpisua Belmonte, J.C., (2017). Interspecies Chimerism with Mammalian Pluripotent Stem Cells. *Cell*, 168(3), 473-86 e15; <http://dx.doi.org/10.1016/j.cell.2016.12.036>

³ Karpowicz, P., Cohen, C., and van der Kooy, D. (2004). Is It Ethical to Transplant Human Stem Cells into Nonhuman Embryos. *Nature Medicine*, 10, 331–35.

⁴ Roeser, S. (2010, 10). Emotional Engineers: Toward Morally Responsible Design. *Science and Engineering Ethics*, 18(1), 103-115. doi:10.1007/s11948-010-9236-0.

Disease mongering - the case of advertising drugs for restless legs syndrome in Poland

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Disease mongering is sometimes described as a worrisome manifestation of the progressive medicalization of life. What is more, it undermines confidence in the objectivity and beneficence of contemporary medicine and science. Is the promotion of restless legs syndrome in Poland an example of disease mongering?

The objective of disease mongering is to increase the sale of a specific drug by promoting or even inventing new diseases. Numerous techniques can be used to achieve that goal: such as DTC (direct-to-consumer) mass advertising in case of over-the-counter drugs or social campaigns and sponsored articles in medical journals in case of reimbursed drugs. There is a lot of ways to make the public opinion believe that a certain disease is serious and widespread.

During the presentation the current state of ethical debate on disease mongering will be summarized. Theoretical and normative considerations will be based on the analysis of a case study - actual advertising campaigns of restless legs syndrome in Polish media.

There is a number of challenging questions on that matter. Is restless legs syndrome a disease? Who, why and how has been selling medicines for that indisposition? Finally, why should bioethicists care about it? The goal of the presentation is to try to answer for all of those questions.

Comparative mapping of casuistic methods in bioethics teaching: a pilot study

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Casuistry has a strong relevance in the history of European moral philosophizing, but also has a strong presence in contemporary fields, like applied ethics or bioethics. Toulmin and Jonsen certainly had a significant and direct impact on the revival of casuistry in moral philosophy and also on the wide acceptance of concrete case analyses methods in education. The usage of casuistry is especially prevalent in various ethics education programs at graduate and postgraduate levels. There is hardly any course or educational program in applied ethics that totally avoids the usage of one or another kind of casuistic methods or approaches for ethical case analysis. This study collected a variety of competing methods used in web-based courses on health care ethics or bioethics, and conducted a literature review on papers focusing on casuistic methods in ethics teaching. In this presentation we wish to show the results of this comparative mapping study conducted on available methodologies for ethical case analyses.

Transmission of information related to family genetic diagnosis

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Genetic test results often have implications not only for the patient but also for his family. When genetic counselors meet the person who give the genetic results, the question arises how to increase the opportunity that the patient will not refuse to transmit information (that could prevent disease, and prevent suffering) to members of his family. We shall try to give genetic counselor tools how to convince people to pass the information to the family. Don't

Display Options- two dichotomous "yes or no" transfer of information. Try to say that "we assume that you will agree we can use the information to prevent disease in your family". This assumes suggestive formulation that makes it more difficult to refuse.

When the patient does not agree talk about motives not to transfer information and refer to them while giving concrete examples of each of the arguments

1. **You may feel guilty** if something happens to a person in the family. **Hiding information** in present time **may be irreversible**.
2. How would you feel if you know that information that could save you, was held secretly by anyone in your family.
3. If the reason not to share information is to fight with a family member: This is revenge that could **hurt you (guilty, rejection in the family** if it becomes known that you knew and hide)
4. **You may punish people who you did not want to punish**: elderly parents, wife ,children, grandchildren.
5. Members of the family may be angry with you if they know you are ill some years an illness that can be genetic and you did not tell them to test themselves.
6. **You have power** to benefit others, and improve family relationships if you tell your relatives to make genetic test.
7. Law and ethics committee may decide to move life-saving information without your consent. Would not you prefer to determine yourself.
8. Genetic counselor feels bad when you refuse to transmit information. You hurt the person that helps you now.
9. If the explanation why he refuses is "I do not want to worry because there is no cure for the disease" You can explain that your relative will be able to plan his life even if there is no cure for the disease. If there will be a drug in the future, lack of information will not allow a person to accept it.

In sum, there is a place to invest much effort in formulating methods of communication with the patient discovered gene carries the disease to not reject the possibility of delivering genetic information to the family. Presentation of the proposed may use complex ways that exploit mechanisms of guilt, self-control, greater awareness and detailed results, and reveal information transfer options as the patient himself.

Completed Life. Could a 'completed life' be reason for legally assisted suicide?

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In 2002 the Termination of Life on Request - also known as 'Euthanasia' - and Assisted Suicide Act (the Act) came into force in the Netherlands. The Act regulates the ending of life by a physician at the request of a patient who is suffering unbearably without hope of relief. The physician will not be prosecuted provided she complies with the due care criteria specified in the Act and reports the case to the municipal pathologist after it has been carried out. The due care criteria are:

1. The patient's request is voluntary and well-considered;
2. The patient's suffering is unbearable and hopeless;
3. The patient is informed about his situation and prospects;
4. There are no reasonable alternatives;
5. Another independent physician should be consulted;
6. The termination of life should be performed with due medical care and attention.

It is obvious that especially the first two criteria leave room for discussion: what is ‘voluntary and well-considered’ and what makes suffering ‘unbearable and hopeless’? For instance, is it sufficient to have an advance directive in case of dementia?

The latest public debate in the Netherlands circles the question if a ‘completed life’ can be reason enough for unbearable and hopeless suffering as meant in the Act, and so makes way for legalized ending of a life. October 2016 the minister of Health, Mrs Schippers, ignored the advice of a ‘commission of wise men’ not to extend the Act, and launched the idea of a ‘social/relief worker in the field of dying’ to assist old people – 75 years and older – with a death wish when they experience their life as completed. The main argument for this idea is the right to autonomy and self-determination. Another argument of the minister reads as follows: “It is not only the duty of a physician to act merciful, but also the duty of the government to show compassion.” In my presentation I would like to analyse the arguments on both sides of the debate and discuss the question: could a ‘completed life’ be reason for legally assisted suicide or euthanasia?

They’re Going to CRISPR People. What Could Possibly Go Wrong?

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This headline from a June 2016 article in STAT by science writer Sharon Begley captures perfectly the simultaneous optimism and skepticism surrounding gene editing – the latest in a long line of novel biotechnologies that we hope and fear will change the world. Gene editing is in fact not especially novel; zinc finger nucleases and TALENs, two gene editing modalities that are more difficult to use than CRISPR/Cas9, have been studied for many years. Yet the discovery and development of the CRISPR modality has rapidly changed science and outpaced science policy. The challenges to be faced include but are not limited to: (1) the apparently unavoidable inheritability of genetic modification if gene editing is used in very early embryos to avoid mosaicism, which can result in imperfect correction; (2) the failure of public, professional, and media discussion to compare and contrast gene editing of embryos with embryo selection, although both require in vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD), and the latter avoids the possibility of unintended consequences; and (3) the use of gene editing in exotic combination technologies designed to grow human organs in animals.

It is known that gene editing has many potential applications in adults with certain diseases and conditions, but the excitement and interest in the technology is generated by the prospect of editing embryos, or even gametes, to eliminate genetic diseases, and the possibility of creating animal organ farms. (The even more suggestive use of gene drives to eliminate insect-borne diseases like malaria and Lyme disease raises a related and still more challenging set of questions.) It has long been known that almost all inheritable genetic disorders could be eliminated by IVF and PGD; there are very few such disorders that cannot be addressed effectively this way. Both embryo selection and embryo editing require foreknowledge of the possibility of passing a disorder on to offspring, and the ability to test for the presence of the unwanted mutation. Why should the uncertainties associated with embryo editing be risked when selection is possible? And why do new ways of augmenting the supply of transplantable organs quickly and without immune system challenges capture the imagination far more readily than the hard work of preventing and treating damage to organs from diseases and their treatments?

The attraction of novelty, the slow pace of genuine and lasting scientific progress, and social and scientific aversion to the basics of prevention and treatment (including attention to public

health measures, reduction of health disparities and income inequality, and improvements in access to basic health care) all contribute to prioritizing groundbreaking science over the hard work of public policy change. Where should bioethics scholars invest their energy? The gene-editing phenomenon provides a useful starting point for this important discussion.

On the undecidable propositions used often, before the proper time, in the descriptions of the successive stages of the embryo – fetal development of human beings

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The stages of the existential embryo – fetal development of human beings are accompanied with packets of possibilities that become real along the evolution of the pregnancy. The possibilities are often opposite and even contradictory e.g. empty or full gestation sac. In the paper will be given some lists of possibilities (and their probabilities) that are present in packets connected with concrete stages of development. The successive stages finish with a reduction of a concrete packet and with appearance of a new concrete packet. But before every reduction each statement that: “this or other possibility is already real” is fully undecidable. The chance that a concrete possibility of a concrete packet will be realized can be predicted only with probability. We can never be certain to which possibility the packet will be reduced. Since every possibility has its own probability to become real and among them there is also the probability to become a human person we have to protect human embryos and fetus against abortion from conception to birth in order to give chance to the birth of a person. But when the chance to become a human being disappears the abortion must be done to save the women. For example, in the case when the embryo became transformed into an empty gestational sac. Other similar cases will be examined in this paper. In each stage of evolution there is the possibility of a spontaneous abortion. It was proven that the frequency of spontaneous abortions reaches to 60 % of gestations. So we are dealing with a natural eugenics and euthanasia. The Nature takes care of the quality of life. Can we do the same when the Nature is not able to succeed?

Future Healthcare Professionals’ Opinions on Ethical Issues Concerning Genetics Tests and Pharmacogenetics

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Advanced technologies of genetic tests (GTs) have become more widely used in recent years and new ethical questions resulting from the improvement in these technologies can be raised. In GTs diagnostics as well as in GTs screening a variety of factors needed to be considered and evaluated in relation to the availability and accessibility of these tests. One example could be pharmacogenetics as personalization of therapy based on a patient’s genetic profile that may decrease safety concerns with medications and even increase effectiveness of therapy. Many ethical, organizational and commercial constraints resulting from the GTs services present serious challenges to healthcare professionals. However, healthcare professionals’ perceptions of ethical, social, legal or practical implications of them fulfilling roles involving the design and implementation of GT services are not widely acknowledged in the literature. Community pharmacists in practice are faced with ethical questions, under what circumstances it is inappropriate to use these technologies and their results, incidental findings

and who should decide about who may be informed of any findings and who ought to be informed. Patients' health records with genetic information are specific medical records.

The current literature reveals that pharmacists are more or less resistant to provide the GTS at pharmacies but very little is debated on the consequences of these attitudes. It may be relatively easy to assess future healthcare workers prospective on these meter. Thus biomedical students could play a key role to help us answering the question: „Who should place restrictions on science, if any?“

Our study aimed to investigate students' attitudes toward GTs and pharmacogenetics. We shall present the results of the survey exploring the attitudes of 350 pharmacy students attending the first and final years of the Integrated Master degree in Pharmacy, from the Faculty of Pharmacy of the University of Belgrade, Serbia, volunteered their opinions on 11 questions concerning GTs and 4 concerning pharmacogenetic tests with some ethical issues they raised. Students' attitudes about pharmacogenetics are positive, most of students agree that it should be available at the community pharmacies and there main concerns are data sharing and data security. Students' attitudes suggest educational strategies to guide how pharmacists may acquire the appropriate knowledge and skills for new health technologies such as GTs and pharmacogenetics, in particular.

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Cognitive Enhancement in Children: A Risk of Creating 'Superhuman' Disabled?

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Human enhancement continues to be hotly debated by both 'professionals' and academics, and increasingly also by the general public. This is no surprise, given that the idea of making human beings *better* – individually and collectively – has existed for centuries. Parents appear to be especially receptive to new ways of improving the qualities of their offspring – first and foremost their cognitive abilities – in the hope of giving them the best life possible. At the same time children as not-yet autonomous persons are vulnerable to the decisions made on their behalf. This dynamic has led to a long-running philosophical debate about the moral permissibility of paediatric enhancement. Unfortunately, this debate has somewhat stalled at the point of disagreement on general permissibility, with both sides strongly relying on the notion of well-being to support their respective positions. Rapid progress in the sciences, including the development of the new CRISPR-Cas9 technique, holds much promise for effective cognitive enhancement in children, and this makes proper ethical assessment an urgent matter. Arguing that enhancement is here to stay and that prohibition is not a feasible option in a globalised world, I suggest that the debate should instead focus on what cognitive enhancement in children is likely to mean for the welfare of children. Addressing the question of whether enhancement of intellectual abilities in children is likely to lead to the creation of 'superhuman' disabled children – that is, children with superior or even yet-unseen cognitive capacities but a disability in some other sense (medical, social or both) – I draw on evidence from various fields, including education, law, disability studies and sociology, to demonstrate that the positive effect of cognitive ability on individual well-being is frequently overestimated and can thus not serve as a moral justification for cognitive enhancement. Furthermore, the current legal environment with regard to children with higher intellectual abilities gives cause for concern about the well-being of future cognitively enhanced children and urges us to address prevailing shortcomings in educational provision before deliberately engaging in the creation of more cognitive potential. Suggesting that any moral judgment

about cognitive enhancement should focus strongly on the ends pursued, I argue that the welfare of children is endangered not so much by the new possibilities and methods of enhancement as by the failure to fully appreciate children's need for the provision of appropriate opportunities to match their individual abilities.

Amplio, Ergo Sum

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What we today refer to as human enhancement technologies and methodologies have had a greater and more fundamental influence on mankind than many would wish to accept. I present here an argument that enhancement, in its various forms, has been essential to the evolution of our species and its use today will only maintain the human continuum. If we can affirm this there are great implications for our understanding of and the attitudes we should adopt towards the beings we may become, the so-called 'posthuman'. It is my contention that by looking to the past we will hold the key to understanding the likely ways in which the 'human' will develop, and react to that development, in the future.

This paper aims to develop a palaeoanthropological bioethics, in order to explore the idea that enhancement technologies have been and will continue to be an essential element of what we might call the 'human continuum', and are indeed key to our existence and evolution. Whereas conservative commentators argue that enhancement is likely to cause us to lose our humanity and become something other, I here argue that the very opposite is true. Using evidence from paleoanthropology to examine the nature of our predecessor species, and their proclivities for tool use, we can see that there is good reason to assume the development of *Homo sapiens* is a direct result of the use of enhancement technologies. A case is also made for broad understandings of the scope of enhancement, based on the significant evolutionary results of acts and technologies that are usually dismissed as 'unremarkable'. These technologies may not be those that we might initially think of as enhancement today, but there is a strong case to be made arguing against the bioconservative position that non-permanent, non-invasive, or non-'technoscientific' technologies and behaviours are just as, if not more, befitting of the description than the modern and futuristic concepts that are discussed. Furthermore, I argue that the use of enhancement by modern man is no different to these prehistorical applications, and is likely to ultimately have similar results. The indication of the argument presented is that technology is an essential element of this human continuum, and *Homo sapiens* is by its very nature an enhanced being. If so, there are powerful reasons to consider our attitudes to any proposed novel being created through enhancement (or other) technology- just as we look back upon our ancestors from whom we have enhanced ourselves, so might the 'posthuman' look back upon us. Technological advances have not made us any more or less morally valuable than our *H. sapiens* predecessors decades, centuries or millennia past, and there is little reason to assume that our enhanced progeny will feel any differently about us.

Truth or Consequences about Brain Death

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There has been a rising chorus of discontent about the justification for accepting brain death as death. Cases of post-mortem pregnancy in which brain-dead pregnant women are sustained

to allow the fetus to gestate and then be removed by Caesarean section and the extraordinary case reported by D. Alan Shewmon in which a whole-brain-dead body was sustained for over twenty years challenge whether brain function is necessary for the continuation of a human life. Assuming that defining death is a strictly biological matter, some bioethicists have claimed that brain death is not really death but a legal fiction. They have also raised the issue of whether the medical community should come clean on the matter and inform the public, especially prospective organ donors and their surrogates, of the current controversy over brain death. Can we honestly obtain informed consent for organ donation when the donors are uninformed about whether the brain dead are really dead? Should the truth be told or does concern about the how the truth might negatively affect organ donation justify perpetuating a legal fiction or “noble lie?” In this paper, I argue that the truth should be told. However, the truth is that defining death is not a strictly biological matter, as critics of brain death incorrectly assume, but involves metaphysical and moral considerations. However, such considerations do not make brain death a “legal fiction.” Indeed, I will argue that biological, moral, and metaphysical considerations strongly support acceptance of the truth that human persons do not survive total brain failure and therefore brain death is really death. If anything, recognition that defining death involves metaphysical and moral beliefs may support a more pluralistic approach to the legal definition of death, rather than perpetuating a noble lie.

What factors influence a healthcare organization’s implementation of new and emerging technologies as treatments for disease?

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New medical technologies are continuously emerging in order to improve the lives of patients, rid the world population of disease, and solve common healthcare problems. As the primary providers of healthcare, hospitals and medical facilities are faced with the challenge of implementing new techniques or treatment interventions while maintaining a high level of efficiency and success. The integration of modern technologies as treatments for disease is affected by multiple factors.

The safety and efficacy of the specific intervention method should be the primary focus when introducing a technique or procedure into a healthcare environment. Patient safety must be a priority to ensure that a hospital is doing its duty to provide reliable healthcare that promotes patient benefit; a medical facility is accountable for ensuring the highest level of success that is possible when treating its patients.

Furthermore, when a decision is made to implement a new medical advancement, a healthcare organization must determine whether the technique or treatment and its ensuing ethical implications correspond to the moral values held by that institution. Controversial techniques, such as genetic enhancement, may cause moral distress to individual employees, as well as to the institution as a whole, demonstrating the need to evaluate and discuss ethical implications and the solutions that ensure safety and efficacy of application. An institution must establish and abide by a firm set of values and goals to enable it to deal practically with all aspects and services of their institution, including new medical advancements.

If and when a new technology has been approved for use, it is crucial that the appropriate policy or protocol is created to ensure that both patient welfare and organizational moral agency are considered. While a government may promote an approach that is universal to an entire medical community, each institution also has the responsibility to create and maintain a successful system for new treatments. This policy or protocol should clearly reflect the best

interests of individual patients, the staff who are administering the intervention, and the organization as a whole. Ideally, all of these parties should be satisfied.

Two potential technologies that are emerging in healthcare, and to which the ideas outlined above can be applied, are genetic therapies and genetic enhancement. While neither of these new medical advancements are, as of yet, fully developed, nor being implemented within individual healthcare organizations at this time, it is important to consider how hospitals, for example, are going to approach these new interventions and include them into their system of care. Controversy surrounds many genetic techniques, and institutions should begin to prepare for the unknown, to ensure that patient safety is considered, their organizational values are upheld, and that the techniques can be implemented through an effective protocol. All of these steps will contribute to effective and advancing medical care for society.

Preimplantation genetic diagnosis: Ethical and legal controversies

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Preimplantation genetic diagnosis (PGD) is the genetic testing of embryos created through in vitro fertilization (IVF) before selection of embryos for transfer to a woman's uterus. Initially, PGD was developed as an alternative to traditional prenatal genetic diagnosis, such as amniocentesis or chorionic villus sampling (CVS), in order to prevent termination of pregnancy in couples with a high risk for offspring affected by a genetic disease. However, PGD opens possibilities for realization of additional, ethically more controversial goals. Some of the more controversial uses of PGD are: HLA matching to save an older child, non-medical sex selection and selection for disability.

In the first part, ethical controversies surrounding possible uses of PGD will be analysed (the place of human dignity within bioethical debates on PGD will be highlighted). Special attention will be given to the problem of preconception sex selection for non-medical reasons. By using the "life as a novel" metaphor (Dworkin) and with reference to the argument of the child's right to an open future (Davis), the practice of non-medical sex-selection will be identified as ethically problematic. In the second part, legal treatment of PGD in various national legislations will be explored. The relevant case law of the European Court of Human Rights will be analysed as well. Finally, normative framework of PGD application in Bosnia and Herzegovina (its entities) will be briefly examined (including the relevant provisions of the codes of medical ethics and deontology, adopted by the entity medical doctors' chambers). Possible modifications of current regulations will be suggested based on the experience of other countries.

E-health beyond technology: analyzing the paradigm shift that lies beneath.

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Information and computer technology has come to play an increasingly important role in medicine, to the extent that e-health has been described as a disruptive innovation or revolution in healthcare. The attention is very much focused on the technology itself, and advances that have been made in genetics and biology. This discovery-oriented view leads to the image of e-health igniting a medical revolution. We argue that this account is too narrow and propose the integration of a problem-oriented view in order to answer the following questions: What is changing in medicine today concerning e-health? To what degree could

these changes be characterized as a ‘revolution’? By applying the work of Thomas Kuhn, Larry Laudan, Michel Foucault and other philosophers – which offers an alternative, problem-oriented understanding of progress and revolution in medicine to the classic discovery-oriented approach – to our analysis, we come to a different interpretation of the e-health revolution. The classic, long-standing paradigm in medicine could be described as curative or reactive: medicine comes into action when symptoms occur. Three factors currently put strain on this curative paradigm: the aging population, a significant increase in chronic diseases and the development of more expensive diagnostic tools and therapies. This promotes a shift towards a new paradigm with an emphasis on preventive and proactive interventions. Although curative elements still play an essential role, P4 medicine reflects many characteristics of the new preventive paradigm. This problem-oriented approach changes the focus from the technology itself towards the underlying paradigm shift in medicine. We will discuss the relevance of this approach by applying it to the surge in digital self-tracking through health apps and wearables. In a curative setting, Gadamer describes health as an enigma: we are generally unaware of our healthy condition until illness creates a disturbance. However, in a preventive paradigm, we can describe the phenomenon of self-tracking as an inversion of the enigma of health. A focus on chronic disease and lifestyle factors also creates a shift towards individual responsibility: a disease is transformed into a manageable affair. Hence, a preventive discourse specifically aimed at controlling the epidemic of chronic diseases, requires a constant awareness of our health status. Self-tracking devices can satisfy this need. We argue that incorporation of a problem-oriented view on medical (r)evolutions allows for a much more fine-grained understanding of the current developments in e-health and medicine.

Ontology and germ line genetic enhancement

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This paper seeks to answer the question: What does ontology, understood as a theory of existence, have to do with the ethics of germ line genetic enhancement? This paper presents an evaluative framework of connections between various answers to the broadest question of ontology regarding the nature of existence and ethical questions regarding germ line genetic enhancement.

The paper proceeds in three parts. First, I present a brief argument as to why general ontology is relevant to ethical questions in biotechnology. I argue that how we view the nature of existence has particular bearing on how we view the nature of our own existence. In addition, I argue that one's theory of existence has direct implication on how we should view the future of our existence given the advancement of genetic manipulation and enhancements. Second, I sketch three possible answers to the question: What is existence? In this section I provide an overview of existence as: 1) essential exemplification, 2) monistic physicalism, and 3) idealism. Third, I show how each of these answers to general ontology have very different ethical implications regarding whether or not germ line genetic enhancement is a good thing for human well-being. Fourth, I offer a brief evaluation of the implications of each of the three views of existence on the question of whether germ line enhancement is good for the future of human beings.

Human enhancement and human capabilities

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Although bioethicists have spilled gallons of ink in discussing issues around human enhancement, there is still little consensus on how enhancement should be evaluated. One of the most promising ways to describe human enhancement seems to be the one that connects enhancement with human well-being. However, in this case one is faced with well-known issues of coming up with a defensible account of human well-being. Recently Johann Roduit (Roduit, 2016) have defended the view, that human enhancement should be evaluated by using the capabilities approach developed by Martha Nussbaum and Amartia Sen. Roduit thinks that there are at least three reasons why capabilities approach should be considered as the best conception of human perfection. First, it provides an objective ideal of what a human being ought to be. Second, it is flexible enough to allow room for pluralism and political deliberation. Third, it provides guidance and not only restriction. In my presentation I am going to examine Roduit's proposal and show that the capabilities approach is not as promising approach as far as the evaluation of human enhancement is concerned.

Concepts of Hope in Clinical Medicine and Medical Research

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Context: Hope is a fundamental anthropological concept both in clinical medicine, in medical research and in ethics consultation. Hope is used as an argument both in the clinical process of decision making about different therapeutic options and in strategies of medical research, including novel therapeutics, regenerative medicine, genome editing, and enhancement. This way, hope becomes a normative category in medical and research ethics.

Objectives: What different conceptualisations of hope are referred to by physicians, scientists, nurses, patients or the public in general? What recommendations can be derived both for ethics case consultations and the public debate about future medicine, to adequately address this topic?

Results: Hope is a concept that includes qualitative, quantitative and relational dimensions alike. Physicians and scientists usually reflect the *qualitative dimension*: A common notion during ethics consultation or health technology assessment is that there is either hope or not. Apart from that, ethicists should encourage the *quantitative dimension* of hope: Many patients or healthy citizens indicate that they have more or less hope concerning (future) medical options. Beyond that, the *relational dimension* is crucial both in clinical and research ethics: What are the specific hopes of patients or citizens in their respective situations? What are these hopes related to, what are the (future) therapeutic aims patients might want to strive and suffer for, and the public might want to pay for? Sometimes these hopes relate to healing, sometimes to life prolonging treatment, sometimes rather to aspects of quality of life, and sometimes to non-medical, even transcendent wishes. The hope to enhance general human living conditions differs from the hope for a meaningful death.

Discussion: Ethicist should be prepared to listen to the language used by patients or the public concerning individual or general hopes and fears. It is crucial to realise that all groups involved in therapeutic medicine or medical research have a certain amount of hope concerning specific personal or general aims. Hopes can serve as a bridging concept to better understand individual preferences and wishes. Therefore the conceptions of hope, presented in this paper, can support the moral quality of decision making in medicine and research.

Balancing enthusiasm and restraint: Ethics and prudential adoption of genomic sequencing in clinical practice and public health

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Emergent methods of DNA sequencing allow us to look more closely at the human genome than previously. Sequencing is fast and inexpensive, and is a key driver behind precision medicine. Genomic testing is often an appropriate course of action, such as increasing diagnostic yield for those living with rare disease. Alongside this, however, lie concerns over ‘technology-led’ implementation. Additionally, the volume, complexity, uncertainty and dynamic nature of the information gleaned from genomic testing are relevant to its ethical consideration.

This paper will propose the concept of ‘prudential adoption’ of genomics. Case studies in genomic sequencing, in both clinical and public health contexts, will be critically analysed to help build the claim that there is a key role for prudence when new biomedical technologies are being implemented. After outlining some of the considerations relevant to genomic diagnosis and prognostication (such as penetrance, and the current status of interpretive databases), the paper will move to discuss how ‘prudence’ might be useful to genomics, in both clinical practice and public health domains. This necessitates a need for balancing individual benefits and population harms; optimising the critical application of concepts such as autonomy and determining whether differing ethical standards – such as a ‘broad’ conception of best interests – might apply to different contexts for genomic testing.

Consent and uncertainty in biobanking and biomedical data mining

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In this paper, I compare the ethics of consent under uncertainty in two important biomedical contexts: first, biobanking, the collection and storage of tissues and genetic material for scientific research; and second, biomedical data mining, the practice of collecting and analyzing large amounts of biomedical data for clinical and research purposes.

A widely debated ethical problem for consent in biobanking is that there is uncertainty about how samples can and will be used in the future, which poses a basic obstacle to informed consent when donating these samples. In this practice, tissues or DNA samples are taken for use in an indefinite and uncertain range of future research purposes (Beauchamp 2011, 519–21). As Van de Poel writes, “Consenting to an experiment with unknown hazards seems to entail accepting all hazards that emerge from the experiment. It is hard to see how people could rationally accept such experimental conditions.” (2011, 287).

In the case of biomedical data mining, it is widely held that the potential uses of so-called “big data” are, and should be, open at the time when the data are collected. But if the uses are open, then they are uncertain. Arguably, it is not possible to give informed consent under these conditions, because “informed” seems to imply having some knowledge of the things to which one is consenting. This has been highlighted as one of the most important ethical conflicts surrounding big data applications in biomedicine (Mittelstadt & Floridi 2015).

As a solution to the problems associated with consent to biobanking, many ethicists and practitioners have proposed adopting a practice of broad consent, in which advance consent is

given to an unspecified range of future uses of biobanked materials, with some content and procedural restrictions (Grady et al. 2015, 35).

In both domains, I argue that we should conceive of the difficulty of consent as having two dimensions, a predictive dimension regarding possible outcomes, and a confidence dimension concerning the intentions of the entity holding the biosample/data. The predictive dimension is the difficulty to which broad consent, as conventionally defined, tries to respond. The confidence dimension has to do with establishing confidence in the intentions of the entity that holds the biosamples.

The empirical evidence is consistent with this distinction. Many people who have doubts about giving broad consent are concerned about who comes to possess their samples and information (Garrison et al. 2015, 6–7). Some minority groups are more reluctant to grant broad consent.

This distinction allows us to understand and better respond to problems of uncertainty for consent. A different practice of consent could potentially allow a donor to affirm her confidence in the biobanker, but it would require more than just a new, broader verbal formulation. The content of legitimate consent lies in the expressed intention of one party to treat another party in certain ways in the context of a relationship — as well as institutional arrangements that make these assurances and the intentions that back them plausible to believe.

References

- Barocas, S. & H. Nissenbaum. (2014). Big data's end run around anonymity and consent. In J. Lane, V. Stodden, S. Bender, & H. Nissenbaum, eds., *Privacy, Big Data and the Public Good*. Cambridge University Press. Pp. 44–75.
- Beauchamp, T.L. (2011). Informed Consent: Its History, meaning, and present challenges. *Cambridge Quarterly of Healthcare Ethics* 20: 515–523.
- Garrison, N.A., N.A. Sathe, A.H.M. Antommaria, I.A. Holm, S.C. Sanderson, M.E. Smith, M.L. McPheeters, & E.W. Clayton. A systematic literature review of individuals' perspectives on broad consent and data sharing in the United States. (2015). *Genetics in Medicine*, DOI 10.1038/gim.2015.138
- Grady, C., L. Eckstein, B. Berkman, D. Brock, R. Cook-Deegan, S.M. Fullerton, H. Greely, M.G. Hansson, S. Hull, S. Kim, B. Lo, R. Pentz, L. Rodrigues, C. Well, B.S. Wilfond, D. Wendler. (2015). Broad Consent for Research with Biological Samples: Workshop Conclusions. *American Journal of Bioethics* 15, 9: 34–42.
- Manson, N. & O. O'Neill. (2007). *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press.
- Mittelstadt, B.D. & Floridi, L. (2015). The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts. *Science and Engineering Ethics*, DOI 10.1007/s11948-015-9652-2,
- van de Poel, I. (2011). Nuclear Energy as a Social Experiment. *Ethics, Policy & Environment* 14: 285–290.

Exoskeleton for gait training in spinal cord injured people: Should I respond to the budget or to the person?

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This work gathers some considerations about ethical issues related to the use of robotic exoskeletons for gait assistance in SCI people, with special attention to ReWalk exoskeleton. According to recent epidemiological surveys 2.5 millions of people affected by a Spinal Cord Injury (SCI) are experiencing a variable degree of disability. In Europe there are 300.000 people with a SCI. This means that, every year, from 250.000 to 500.00 people all around the world are having a SCI. During the last 6 years the branch of bioengineering applied to SCI rehabilitation has progressively introduced a few powered exoskeletons. This device is actually available in two different versions, one for hospital training and one for home based

use. This last one can be eventually provided to the patient when a sufficient level of competence has been reached after a training period in a rehabilitative setting.

Financial coverage of home ReWalk version is still under debate and, for most of the patients, it depends mainly by personal resources as so far home delivery is not supported by common and shared International provision rules. Where real economic difficulties exist, should the physician present this instrument a priori also as a “tool for domestic use” or should he/she not inform the patient about this possibility?

This instrument appears to be a proportionate treatment for those patients affected by SCI. The quality of life appears to have benefited from the improved motorial skills offered by the exoskeleton. But the excessive costs (around \$70,000.00) seem to influence the purchase for home use. In particular, the choice should not only be the patient's, because the hope of a possible increase in his/her functions and quality of life may be compromised. Good medical reasoning starts from a balance between risks and benefits, and the use of the exoskeleton entails many of benefits. But the ethics issue, and not only the clinical issue, concerns what type of information the physician should offer the patient. It also concerns resolving an ethical doubt: is it more correct, in any case, to inform the patient who will certainly improve (but not as he would if he had the tool at home) or would it be more ethically correct to choose not to inform the patient a priori about this possible improvement in performance using the device at home (unless he is the one who specifically asks)?

If on one hand the patient's autonomy of choice should be always maintained, even in the case of refusal of treatment for economic reasons, on the other the patient's word may not be the only one to be taken into consideration. The patient often needs the doctor's word. In particular one can speak of an essential good doctor-patient relationship in which special attention is asked to be paid by the doctor to the possible difficulties that the patient might have to face knowing that his therapy would be more effective if continued at home, but that he does not have the possibility of buying the exoskeleton.

Biobank research and providing information about health risks

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Should individuals be informed about possible health risk regardless of their wish to know? In Iceland, where the framework of leading company in genetic research does not assume that individuals should be contacted for clinical purpose, the company is asking for permission to inform people of their genetic risk, for instance every woman in Iceland with the BRCA mutation. In this paper I will discuss the Icelandic case with the focus on arguments for and against changing the present framework of biobank research. My argument will show that informing people does not only require minimum changes in the framework but will challenge the boundaries between biobank research and health care in profound way.

Emerging technologies and vulnerable people: The case of assistive technologies for persons with dementia

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Dementia has emerged as a problem to be tackled by various assistive technologies, for example, mobile safety alarms with GPS positioning, fall detectors and adapted internet for social contact. However, persons with dementia are vulnerable, suggesting that such

technologies should be used with caution. It is a common experience among care professionals that persons with dementia often show resistiveness to care. This resistiveness is an indication of their vulnerable condition. They are sometimes not aware of what is in their best interest. In this paper I discuss how to handle resistiveness to assistive technologies among these patients. Some assistive technologies for persons with dementia can be beneficial provided that they are used with special consideration of their vulnerable condition. However, it can be a delicate task to overcome resistiveness while at the same time respecting their autonomy. I suggest how this can be done in a stepwise manner. Special attention is given to the concept of nudging. I also indicate under which circumstances some form of coercion might be justified.

Donation after circulatory determination of death and dead donor rule

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According to the widely accepted in transplantation ethics dead donor rule, vital organs such as heart or whole liver might be transplanted only after death of a donor. This ethical principle is strongly connected with deontological prohibition of murder. In recent years, the debate about donation after circulatory determination of death (DCDD) gains increasing attention in literature concerned with transplantation ethics. Organs procured in this way become an increasing part in the total pool of organs transplanted worldwide. Great Britain might be good example, which depicts this tendency. In this country 87 organs were transplanted in 2004 after determination of death by circulatory criteria. That constituted only 11% of all transplants from deceased donors that time. But in 2015 there were 505 donations after circulatory determination of death, which constituted almost 40% of all transplants from deceased donors performed that year.

As we can see, when vital organ procurement is considered, death might be determined not only by means of neurological criteria but also using circulatory criteria. Under relevant limb of Uniform Determination of Death Act, an individual is dead if he or she sustained irreversible cessation of circulatory and respiratory functions. In United States the exact procedures associated with circulatory determinations of death in such circumstances are stated in DCDD protocols, which vary among different medical centers. Some of these protocols are controversial, especially those, which allow for determination of death after shorter than five minutes period of cessation of circulation. In Poland the exact procedures for circulatory determination of death, when organ donation is considered, are stated in the special Decree of Minister of Health. According to this law death might be determined if cessation of circulation was observed at least for five minutes. During this period of “death watch” physicians, if it is possible, determine the absence of brainstem reflexes such as pupillary light reflex, corneal reflex, vestibulo-ocular reflex and the absence of respiratory functions.

Is it appropriate to determine that individuals whose circulatory cessation is observed only for few minutes are dead? Or maybe some of those individuals might be killed by physicians during organ explantation? Main task of the presentation would be to answer these questions. I will discuss the role of circulatory determination of death, claiming that it is a reliable criterion only because of the fact that it leads to brain criterion. Accordingly we do not need to determine that circulatory cessation is irreversible to be sure someone is dead. We just need to know what is the exact period of cessation of circulation that is sufficient for total brain failure (brain death) to occur.

What will be the impact of emerging technologies on public health? An interactive workshop

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What will be the impact of emerging technologies on public health? That is the main question of the Technology Outlook as part of the upcoming 2018 Public Health Status and Foresight (PHSF). The PHSF is produced every four years for the Ministry of Public Health, by the Dutch National Institute for Public Health and the Environment (RIVM).

As a first step in the current Technology Outlook, 6 major developments with high impact and high level of certainty were identified: Genomics, Internet of things, Robotisation, 3D-printing, Virtual reality, Big Data and E-health (based on literature survey, in-depth interviews, expert sessions and public workshops).

Secondly, the impact on public health was and is being discussed regarding four dimensions of public health: ('classic') health, autonomy, participation and expenditures. These four build on the previous PHSF which presented four perspectives on public health, each representing different values and motives, challenges and policies: -In the Best of Health: a long life in good health; -Everyone Participates: social participation and equity; -Taking Personal Control: autonomy of citizens and patients; -Healthy Prosperity: sustainability of health care expenditures and welfare (<https://tinyurl.com/jofjqd3>). Since 2014, these perspectives have found their way to a myriad of users in many different areas in Dutch society.

In this interactive workshop we will focus on how public health policy makers can or should deal with these developments in technology. First we will together explore which are major questions for policymakers posed by the technological developments, especially regarding the public health dimensions of autonomy and participation. Then we will collectively and structured try to come up with suggestions to policy makers in how to deal with these questions.

Robots in care of persons with dementia

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Robots are being increasingly used in care of persons with dementia (PwDs). Assistive technologies (ATs), including robots "are to be put to use to take care of people with dementia in order to enhance their wellbeing, autonomy and independence, thus enabling them to live independently for longer" (Gordijn & ten Have, 2016). Robots are also likely to be used in care homes for the elderly and for people with intellectual disabilities and others who no longer are capable of living independently.

Amongst the best known of these is AIST's PARO - a therapeutic robot which looks like a baby seal (with antibacterial fur) designed to help in the care of people with dementia. Its designers claim that it has been found to reduce patient stress and their caregivers, to stimulate interaction between patients and caregivers to have a psychological effect on patients, improving their relaxation and motivation and to improve the socialisation of patients with each other and with caregivers (PARO Robots, 2014).

The question this paper will focus on is the question of moral hazard. In economics, moral hazard arises when a party protected from risk acts differently than it would if it were fully exposed to the risk. The development of robots has the potential to create a type of moral hazard in relation to how we as a society deal with care for PwDs. For instance, as robots

become more sophisticated and better able to take care of the elderly, there will be less incentive for people to visit, converse, or interact with PwDs. There is also a risk (common to many professions) that technologies will reduce the workforce. Previously, care for the PwDs meant jobs as nurses and associated carers; with the development of robots, these jobs will likely disappear. There exists the potential for a technologically sophisticated society to ignore the presence of PwDs almost completely. This may have social costs that are not easily quantifiable – loss of respect for PwDs, loss of empathy, a cult of youth, loss of opportunity to cultivate virtues associated with caring for PwDs, loss of humility, loss of the presence of PwDs in society.

Human reproduction/nature as the object of technoscience

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Within the ethical debate on the permissibility of genome editing, it is commonly argued that we have to differentiate sharply between possible somatic gene therapies and the systematic manipulation of the human germ line. The need for such a distinction is often motivated by pragmatic and/or consequentialist arguments, i.e. that the consequences of a manipulation of the human germ line are much harder to predict and potentially affect a greater number of human beings than the somatic gene therapies. (1) It is part of the logic of these arguments that the difference between both fields of application will disappear once they have to be judged as equally safe. This raises the question of whether and how the transition from a theoretical concept to a safe therapeutic option can be achieved in practice. This issue will be discussed in the first section. In contrast to the just mentioned line of reasoning, some scholars argue that beyond the question of safety there are some categorical differences, too. The manipulation of the human germ line is seen as a severe intervention in human nature that has to be regarded as an impermissible instrumentalisation, or/and an infringement of the individual's right to autonomy. Some aspects of these deontologically inspired claims will be discussed in the second section. The third section addresses the objection that genome editing is making human reproduction and/or human nature the object of a technoscience. The considerations will primarily restrict themselves to the use of human germ line manipulations in order to prevent or minimize the risk of severe genetic disorders. (2) The issue of so-called designer babies will not be at the centre of the present considerations, although it will be shortly addressed at the end of the third section.

Notes

1 The German Embryo Protection Act from 1990 follows this line of reasoning as it bans the manipulation of the human germ line primarily out of safety reasons and explicitly excludes somatic gene therapies from its restrictions, which reflects a line of reasoning that is chiefly based on the logic of technology assessment

2 i.e. an implementation that follows the current restrictions on preimplantation genetic diagnostics (PGD) in Germany Art. 3a Embryo Protection Act

Merging With Our Technology: Some (Bio)ethical, Legal and Societal Implications of Human Cognitive Enhancement through Brain-Computer Interfaces and Brain Implants

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Recently, several prominent figures have publicly warned of the potential dangers of developing advanced Artificial (General) Intelligence (AI) or superintelligence, for example Elon Musk and Stephen Hawking, although many other researchers and entrepreneurs have already extensively published on the topic before that, for example Ray Kurzweil and Nick Bostrom. One of the concerns about AI in terms of machine intelligence competition is that as computational technology can increasingly perform and also exceed humans at tasks that were once exclusively in the human domain, (unenanced) humans will relatively rapidly become (intellectually, cognitively, in terms of work/jobs) obsolete. Thus most of the mentioned authors put forth the imperative of interconnecting humans with external computational devices and other technologies in a more intimate, direct manner, using brain-computer interfaces (BCI) and brain implants.

In the discourse on Human Enhancement, much attention has been given to Cognitive Enhancement in terms of using pharmacological substances (e.g. dietary supplements/nootropics, prescription drugs, illicit drugs) and non-invasive brain stimulation (NIBS) (e.g. TMS, tDCS) to enhance the (average existing) capabilities of healthy people. Such enhancement means have been investigated from neurotechnical and pharmacological angles as well as from the viewpoint of their (bio)ethical, legal and societal implications. Much less attention has been given to such aspects and implications of BCI and implants, not least because they are still mostly on the speculative horizon, or at best in early R&D, at least so far as their enhancement application in healthy people is concerned. On the other hand, while drugs and NIBS can generally only work on enhancing existing and necessarily limited neurophysiological structures, BCI and implants potentially offer more profound possibilities of vastly extending existing human mental capacities by connecting us directly with more massive and powerful external computational resources and other capabilities-extending devices. With the first, we can talk of HE within the boundaries of existing capabilities attainable by the biological homo sapiens, while in the latter, we can talk of possibly truly transhuman or posthuman types of enhancement. All this opens many profound questions and issues, ranging from what such HET mean at the level of philosophical and psychological issues, to what the future bioethical discourse and the legislative and governance landscapes regarding such neurotechnologies might look like in the future (issues of justice, access, fairness, etc.).

The presentation will thus focus on first providing an overview of the state of the art and projections of BCI and implants development in terms of HE, and especially what they might mean, inter alia, for individual bodily perception, self-identity and hyperconnectedness, as well as creativity and intuitive insights. We will also investigate what the (re)integration of such cognitive technologies into our internal mental environment might mean for reversing the trend of externalizing (offloading) our mental (computational) processes to independent algorithms, considering the issues posed by the idea of complementary and competitive cognitive artifacts, as recently discussed by David Krakauer. We will then turn to the (bio/neuro)ethical, legal and societal implications, including what some of the national ethics advisory bodies in Europe have proposed regarding the policies for addressing the enhancement uses of such neurotechnologies. Finally, by taking into account all we have discussed, we will assess the ethical and moral imperative of merging with our (cognitive) technology as described at the beginning.

The emerging normativity of aneuploidy testing in PGD

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In 2010, the European Society of Human Reproduction and Embryology (ESHRE) has recommended *against* routinely offering preimplantation aneuploidy screening in combination with IVF. However, there is growing evidence that at least in some defined groups of women, aneuploidy testing could indeed increase pregnancy rate and reduce the risk of miscarriage. Some fertility centres do already routinely offer such tests in combination with IVF. Therefore, we need to distinguish between (i) aneuploidy *tests in special cases* from (ii) preimplantation genetic *screening* (PGS), both in the context of fertility treatment. In addition, evidence about aneuploidy may be available when doing a test for unbalanced chromosomal translocations, or for monogenic diseases in preimplantation genetic diagnosis (PGD). The ethical implications of all these cases need to be clarified.

The current legal situation in Europe is diverse. Germany for instance, within a restrictive regulatory framework, seems to not generally exclude PGD to detect a maldistribution of chromosomes in an embryo; but testing would require approval by a PGD ethics committee on a case-by-case basis and a well-reasoned application by the concerned woman. Switzerland on the other hand allows aneuploidy testing in combination with all IVF.

The paper first examines the ethical justification for offering preimplantation aneuploidy tests. Is it (i) pregnancy rate, (ii) baby take home rate, (iii) healthy, or (iv) "normal" baby take home rate, or is it (v) the reduction of the risk of miscarriage and stillbirth? Then, the paper distinguishes and discusses different types of cases and their moral implications: Testing for aneuploidy can (A) be the main reason for IVF, which in itself would not be medically indicated; or (B) IVF is done as infertility treatment, in which case PGD and aneuploidy testing could be done additionally; or (C) PGD with IVF is performed, in order to prevent a congenital disease or chromosomal translocation, and can include a diagnosis of aneuploidy as (C1) an incidental but unavoidable, or (C2) as an additionally requested finding.

I will argue that the "indirect eugenics" concern, i.e. prevention of discrimination against people with Down Syndrome, Turner Syndrome and other aneuploidies may oppose case (A), but it does not oppose testing in cases (B) and (C). Yet there are also at least three ethical arguments in favour of aneuploidy testing: the "good practice" of IVF, which is directed to ensure live birth, the duty to the emerging child and the parent's right to have a voice.

Aneuploidy testing is a good example for what Peter-Paul Verbeek has called the emerging "morality of things". There is normativity not inherent in technology itself, but emerging in changing circumstances and constraints of the social practices of using molecular genetic technology in the prenatal sphere.

Moral rectitude or eugenics bias? – Considering biotechnological enhancement in sport, academia and elsewhere

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American bioethicist Eric Juengst has argued on numerous occasions, but never more persuasively than in the book chapter, "Appeals to Human Nature — Managing Our Legacies, Loyalties, and Love of Champions" (*Bioethics, Public Moral Argument, and Social Responsibility*, Routledge 2012, King & Hyde, Ed.), that disapprobation of enhancement in athletic performance is by equal measure at odds with the innate human drive toward self improvement, and in keeping with the proclivity in animal societies toward stratification and

its attendant disempowerment of those regarded as “lesser.” In a discussion of so-called gene doping, Dr. Juengst encapsulates this assessment as follows: “[G]ene doping is wrong for athletes to pursue and sports medicine to provide because it compromises the ability of sport to segregate and elevate *genetically advantaged* athletes from their disadvantaged competitors, which is a key element of the spirit of sport and one of the intrinsic values of the enterprise. This will be true even if gene doping is proven safe and effective, and even if it could be provided equitably to every competitor in non-coercive ways.” [Emphasis added.] This, as Dr. Juengst elucidates elsewhere in the chapter, is an argument that is firmly situated in the ethos of eugenics, albeit in a more benign context than is typically associated with the term.

This paper will argue, however, that, given the penalties imposed upon those judged to have violated governing sports bodies’ sanctions against banned substances (e.g., suspension from international competition in Olympic-class sports for periods ranging from many months to years, and having the details of the violation and the suspension entered into a public registry [Cf. United States Anti-Doping Agency Sanctions*] — in effect rendering the athletes unemployable for at least the duration of the suspension), one could hardly describe such responses as benign. Further, that the equation between enhancement and moral turpitude can be problematic outside the confines of athletic performance.

Academic performance regarded as enhanced, although the reactions have not yet risen (or sunk) to the level of an offender’s registry, would nevertheless seem also to conform to the Juengst modern-day eugenics model. A recent documentary on the life of astrophysicist Stephen Hawking (*Hawking* 2013), posits that the aristocratic standard of university achievement in Hawking’s early student career was (and remains) that one should excel without effort — that is, academic achievement, no matter how high, that is the result of great effort and diligence, is by definition proof of intellectual (and therefore genetic and moral) inferiority. It follows from such a perspective that “study drugs” such as Adderall or Ritalin, whether regarded as enhancement or essential therapy, would identify the user as less-than.

Such scenarios raise a number of prior questions, not least being the appropriateness of ascribing moral valence to what, for example, in transhumanism is simply the inexorable advance of biotechnological progress. Or concomitantly, whether the therapy-enhancement dichotomy can be viewed as a way to surreptitiously perpetuate eugenics under the guise of an immutable ethical standard.

Labeling end-of-life decisions as “killing” or “letting die”: a descriptive or normative task?¹ Overdetermination of moral assessments on behaviours described in terms of acts/omissions: An experimental study on the responses to end-of-life cases

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Many bioethicists, including deontologists, have argued that moral judgments on human behaviours depend on the very nature of those behaviours. For instance, “killing” or “torturing” are intrinsically wrong, and could never be morally justified. This is a controversial assumption for consequentialists, who believe that behaviours cannot be morally judged independently of their consequences. Another common --but much less discussed-- assumption in bioethics debates, refers to the way the temporal sequence of the moral judgment is conceived. It is commonly assumed that we first describe behaviours, and only secondarily we make moral evaluations of them. This pattern is particularly explicit in end-of-life debates, where the distinction between “killing” and “letting die” is commonly invoked to justify why “killing” is, all things being equal, more problematic than “letting die”; or why

“killing” should remain legally prohibited while “letting die” should not. Recent years have seen a flood of theoretical and empirical research on the acts/omissions distinction. People tend to judge “acts” as morally relevant and “omissions” as morally neutral. Many reports in the academic literature converge to suggest that acts/omissions judgments shape our moral assessments. Recent empirical studies (Cushman, Knobe and Sinnott-Armstrong 2008) show, however, that moral agents do not necessarily follow that sequence in which they first describe (or see) and then judge (belief): the moral judgment of particular behaviours determines the description that people make about them. In this work, we hypothesize that the order of reasoning is also, in the realm of end of life decisions, the reverse of what has generally been assumed in medical ethics. Our hypothesis is that people who participate in these debates do not judge end-of-life practices as morally / legally acceptable according to whether they are classified as acts or omissions, but the other way around: firstly, they conduct a behavioral assessment as morally adequate or inappropriate, and then unconsciously that valuation is the one that will determine the description of that behavior as active or passive; such as "causing death", or as "letting die". To test that hypothesis, we have designed a questionnaire and psychological manipulations (vignettes and scenarios on end-of-life cases) to be administered to a student population and practitioners or experts with large experience in bioethics. Subjects were presented with morally correct or incorrect end-of-life cases in a between-subjects design. We are in the pilot phase but we present tentative and preliminary results that seem to support our main hypothesis, say, that people’s moral assessments have an impact in their assignment of the action/omission distinction. These findings are suggested to be important for researchers and medical practitioners working in bioethics.

¹ This work was carried out within the framework of the following research projects KONTUZI: “Responsabilidad causal de la comisión por omisión: Una dilucidación ético-jurídica de los problemas de la inacción indebida”; (MINECO FFI2014-53926-R); the research project: “La constitución del sujeto en la interacción social: identidad, normas y sentido de la acción desde la perspectiva de la filosofía de la acción, la epistemología y la filosofía experimental”; (FFI2015-67569- C2-2- P); and the research project; “Artificial Intelligence and Biotechnology of Moral Enhancement Ethical Aspects” (FFI2016-79000- P).

Risk-benefit assessment in biobank research

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A biobank is a collection of human biological material coupled with personal, medical, genetic or other information about individuals who have donated samples to the biobank. Since the late 1990s specimens and data collected in biobanks have become an important resource in biomedical research. To be admissible, all projects of such research must be approved by relevant research ethics committees (RECs; or similar bodies). In this presentation I will focus on ethical and practical problems RECs may face when making risk-benefit assessment in biobank-dependent research.

First, drawing from literature and history of famous real-life cases – such as *Beleno et al. v. Texas Department of State Health Services* and *Havasupai Tribe v. Arizona State University Board of Regents* (Mello & Wolf 2010; Carnahan 2011; Nurmsoo & Hayes 2015), I will analyze various types of risks that may be posed by biobank-dependent research. I will argue that risks of biobank research (i) *always* extend beyond interests and rights of the individual donor to population groups represented by the donor as well as the general public at large, and that (ii) they *always* exists, but are usually low (or even minimal) and mainly of social, legal and dignitary character (Rothstein 2005; Dhali et al. 2013).

Secondly, I will discuss the difficulties of weighing potential benefits to be gained from biobank-dependent research against potential harms for donor, represented populations, and society at large. I will argue that it is difficult for RECs to determine risk-benefit profile of such research, because: (1) the risks and benefits are often heterogeneous and incommensurable; (2) it is still unsettled whether and how risks to groups or communities from which samples donors are recruited (e.g. risks of group discrimination or risks for indigenous communities cultural identity) should be considered (Weijer 1999; Emanuel & Weijer 2005; Santos 2008; McWhirter et al. 2012); (3) it is unclear how should social value of knowledge expected to be gained from the research be understood and evaluated against the risks involved (Freedman 1987; Karlawish 1999; Grady 2002; Casarett et al. 2002; Habets et al. 2014; Wenner 2015, 2017; Wendler & Rid 2017). I will make several suggestions how these problems might be mitigated or resolved in RECs' practice.

Incidental findings: inherent part of patients' identity or unwillingly imposed digitalization?

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Incidental findings, results that exceed the initial indication for a medical test, are of the most contested topics in current debates on genetic testing.

Geneticists stress the inevitably increasing number of incidental findings in the rapidly evolving technique of Next Generation Sequencing (NGS). Whole exome or even whole genome sequencing (WES/WGS) scan the human genetic data to the fullest, allowing a faster and better detection of illness-causing and sought-for mutations. However, they might also reveal supplementary and unsought-for health risks. Therefore, various guidelines have been published on how to handle this additional yet unsolicited medical information (Green et al., 2013). Simultaneously, numerous ethical debates have been raised on whether these incidental findings are an opportunity of self-governance for the patient or, in contrast, a risk towards personal decision-making and autonomy.

Up till now, one voice has remained remarkably silent in this debate, i.e. the voice of the patient himself. Despite the advice of geneticists and the arguments of ethicists, little attention has been paid to the experience of the patient who actually gets confronted with incidental findings, as an inherent possibility of WES/WGS.

To fill this scientific gap, we will, firstly, argue why practice and policy guidelines for incidental findings are in absolute need of an empirical basis in patients' lived experience. Secondly, we will present the first results of our qualitative research project in which we interview patients with a Mendelian disease about their experiences and preferences concerning genetic testing and, more specifically, incidental findings. We will investigate the particular meaning of incidental findings and the impact they have on patients' personal identity and on their psychosocial and family life. Do patients consider incidental findings as a positive side-effect of genetic testing, as an opportunity for knowledge and action (towards themselves, their future and their family), as an inherent part of their identity? Or do they also fear incidental findings as disturbing information they did not ask for, as a possible cause of worries and anxiety, as digital data they cannot control? Leaving the polarization of advocating versus inhibiting incidental findings behind, we aim for an experience-based and contextualized comprehension of incidental findings, as the necessary ground for future guidelines and practice.

Reference:

Green, R. C., Berg, J. S., Grody, W. W., Kalia, S. S., Korf, B. R., Martin, C. L. Genomics. (2013). ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing. *Genet Med*, 15(7), 565-574, doi: 10.1038/gim.2013.73

The pre-informed patient

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E-health has become a new factor challenging the practice of medicine. Primarily, the novel technique of data managing, storage and computing is discussed with respect to security of data and confidentiality. Yet, other aspects that may have a considerably wider impact on medicine tend to be neglected in public debate. Moreover, they touch basic concepts of medicine and, hence, deserve careful examination.

In this paper I will show how E-health and big data in medicine will affect the fundamental principles that guide medical practice. As a central facet I will consider the phenomenon of the pre-informed patient. Often these persons are mentioned as examples of the annoying patients that upset medical practitioners. Yet, such a judgment seems to be rather limited. It misconceives the central role of medical information – and the question who has power over it.

Information related to medicine and health is nowadays available ubiquitously. Yet, out of an infinite set of data information is to be screened which is valued as being related to health and medicine. This often disregarded act reveals that the mere availability of facts challenges medical epistemology. To value facts as health related cannot be delineated by science, instead needs exploring what may be held as illness and disease. In addition, to confine conditions as not related to medical practice confronts providers of care with the intriguing problem of power in medicine: who is to say that a condition shall not be dealt with medically?

Moreover, promoters of E-health state that availability of information will promote health and health-conscious behaviour. Yet, this judgement may turn out as too optimistic a statement. It does not take notice of the gap between knowledge and patient's self-efficacy, i.e. the psychological force to act in a certain direction. Self-efficacy is most effectively enhanced within a dialogue of persons. Hence, the encounter of patients and their physicians turns out to be the most important medical act to increase patients' self-efficacy.

Furthermore, the unlimited flow of information will affect an increasing number of persons/patients by the *nocebo-effect*, which is the complementary side of the well known *placebo-effect*. Awareness of nocebo may have detrimental effects on persons let alone the risk of manipulation of information against which there is no easy protection at hand. Recent research has proven how nocebo-effect has a negative impact on medical treatment in many cases.

Notwithstanding contemporary progress in e-health the pivotal act of medical practise is found to be the personal encounter of patients and their physicians which is to be brought to light by empathetic communication.

Textuality of genome editing: Possible applications and their legal consequences

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Transformations in the life sciences and technologies are altering fundamentally the ways human societies think about what it means to be alive and human, and what rights should be attached to humanness and life in general. According to Sheila Jasanoff, when the structure of the DNA was discovered, humanity entered into the epoch of genetic textuality. The next phase of this new literacy was the completion of the human genome project. More recently, we have reached the third phase of genetic literacy when scientists acquired editorial skills and developed the technology of genome editing. The presentation will focus on the normative challenges this new technology poses. Should regulation guarantee access to genome editing? And, if yes, on what fields? Should patentability take into account moral components in this field? Furthermore, we should also reflect on the broader ethical framework that governs the ethical-legal assessment of this technology. Should we consider it as an enhancement, a therapy, or something else?

German lay perceptions of Direct-to-Consumer Genetic Testing (DTC GT) ¹

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Background: Decreased cost and increased speed of testing today makes it affordable and marketable to consumers, resulting in an (online) DTC GT market. This market works across international borders, ignorant of varying national restrictions in regard to genetic testing (Borry et al 2012). In Germany, users can order tests and obtain results from abroad over the Internet, yet the awareness of DTC GT in Germany appears to be low, since there are no prominent domestic providers. Since its introduction, there has been a considerable debate about ethical implications of DTC GT. Scholars in medical ethics and genetics have, among other topics, discussed the potential for harm as a consequence of knowing personal risk information, whether knowing personal genetic data is a form of empowerment and the question if the commercial provision of genetic tests is a good practice in light of standards of medical ethics. Apart from experts' views on DTC GT, a number of studies have looked for the awareness and perception of DTC GT among the public in some European countries (Cherkas et al 2010; Vayena et al 2012; Mavroidopoulou 2015), yet this topic is still unexplored in Germany.

Research Question: What are German lay perspectives on DTC GT? To what extent are lay persons' views ethical judgements on commercial offers of medical goods?

Methods: Focus groups (n=7) with lay people (participants n=43), qualitative content analysis

Preliminary Results: DTC GT is generally seen critically, with the exception of so-called lifestyle tests. Criticism is based on commercial nature, online distribution model and a perceived lack of professional counselling. Participants' views reflect an ideal of medicine as being in opposition to commercial action in terms of its ideals, professional standards and capabilities.

¹ The research presented is part of the international research collaboration "Mind the Risk. Ethical, psychological and social implications of provision of risk information from genetic and related technologies", funded by Riksbankens Jubileumsfond (The Swedish Foundation for Humanities and Social Sciences).

Moral Enhancement – An issue in adolescent forensic psychiatry?

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Background and aims: Despite a prevalence of violence among young populations, the first department of adolescent forensic psychiatry (AFP) in Switzerland was established in 2011 at the Psychiatric University Hospitals Basel. Its goal is to treat adolescent offenders suffering from severe mental illness to enable social integration with minimal possible delinquency and maximal possible autonomy. The treatment not only follows legal prescriptions, but has genuine moral significance: the adolescents shall become responsible members of a decent society with moral competencies such as empathy or judgement. Treatment might, thus, be understood as a kind of moral education – maybe even moral enhancement. Studies on ethical aspects in AFP, especially on moral education, are rare. This study aims at exploring and categorising ethical aspects observed in an AFP department. What's the significance of moral competencies in AFP? How might concepts of moral education or enhancement help to master its ethical challenges?

Methods: A systematic literature research on ethical aspects in AFP was performed. The study includes a qualitative content analysis of field notes from observations provided by three embedded researchers. 39 meetings of the AFP department (internal/external case conferences, clinical rounds, shift handovers) were observed 4/2016-9/2016. Two researchers analysed the material according to Mayring's content structuring method using a categorical system tested in a pilot study, refined by literature research and an interdisciplinary review process.

Results and discussion: Theoretical literature on ethical aspects of AFP specifies issues referring to, e.g., decisional capacity, criminal responsibility, dual role of forensic psychiatrists, coercive measures, personal freedom, risk assessment, or research. In our study, most of these issues could be confirmed i.e. they were addressed in the meetings. In addition, however, ethical issues referring to moral competencies of the adolescents were identified such as insight, self-evaluation, judgement, integrity, authenticity, having a plan for life, self-control, self-care, empathy, kindness, cooperation, sense of justice, etc. – or the lack thereof such as selfishness, vanity, dishonesty, manipulation, lacking cooperation, discrimination, aggression, etc. These were mainly discussed in a context of moral education, i.e. selective interventions aiming to improve moral competencies. If we understand these interventions as educative techniques, we may speak of AFP as an institution of moral enhancement.

The whole spectrum of ethical issues as addressed by the AFP team can be categorised in seven types: 1. self-determination, 2. well-being, 3. professional duties, 4. moral competencies, 5. justice, 6. diagnostics/assessment, and 7. research.

Conclusions: Ethical aspects are pervasive in the practice of AFP, even when they rarely arise to the level of outspoken conflict. Next to general issues of bioethics, like self-determination or well-being, and specific issues known from forensic ethics, like professional duties or risk assessment, issues about moral competency are highly significant in this field – yet largely unrecognised in bioethical literature. AFP may benefit from an ethical discourse and an awareness regarding moral education and enhancement – at least as much as the whole of psychiatry allowing for a fully professional attitude.

Can we consistently prohibit reproductive cloning while accepting the reproductive use of stem cell-derived gametes?

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Both the *in vitro* creation of patient-specific stem cell-derived (SCD) gametes and reproductive cloning could enable infertile couples to reproduce without the involvement of a third party gamete donor (which is considered a downside of donor assisted reproduction by many). While this prospect was met with moratoria and bans in the case of reproductive cloning, it is met with reserved enthusiasm in the case of SCD-gametes.

The *prima facie* acceptance towards the reproductive use of patient-specific SCD-gametes is notable when compared to the decidedly negative reactions against reproductive cloning. For one thing, those who accept the reproductive use of patient-specific SCD-gametes, but oppose reproductive cloning cannot ground their argument in safety concerns. Reproductive cloning by means of somatic cell nuclear transfer (SCNT) still presents many risks to the offspring, probably due to an incomplete reprogramming of the somatic nucleus to an embryonic state. However, also the process to obtain patient-specific SCD-gametes requires reprogramming of somatic cells and on top of that even more technological interventions that would increase safety risks. Therefore, if safety would be the main argument against reproductive cloning, it should certainly be held against the reproductive use of patient-specific SCD-gametes.

The negative emotions against reproductive cloning, however, probably do not primarily concern safety reasons. Even if reproductive cloning would be safe, many would still disapprove of its use in humans. Opposition against reproductive cloning based on intuitive responses (cf. the so-called 'yuck factor') or judgements about the 'unnaturalness' or 'strangeness' of the technique are not only insufficient to morally condemn it, but could also apply to the reproductive use of SCD-gametes. Also the argument that reproductive SCNT would infringe on the child's unique identity because (s)he would be identical to the somatic cell donor, should be nuanced: we do not consider natural twins to be deprived from their unique identity and they have at least two aspects that make them even more identical than a clone and the person from whom (s)he was cloned: natural twins share the same mitochondrial DNA (whereas the cloned child would have the mitochondrial DNA of an egg cell donor) and they (usually) grow up in the same environment. Furthermore, for those who oppose the intentional destruction of human embryos, the SCNT route for creating patient-specific SCD-gametes would even be a greater moral wrong than reproductive cloning: while the former inherently involves embryo destruction, the latter does not (the iPSC route also avoids embryo destruction).

This paper aims to explore the various arguments against reproductive cloning and to compare these to the reproductive use of patient-specific SCD-gametes. It is questioned whether we can consistently maintain a prohibition on one technology (in this case reproductive cloning), but not the other (patient-specific SCD-gametes for reproduction).

The evolving market for direct-to-consumer genetic testing and the ethical implications implicit in such changes

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Background: Direct-to-consumer testing assays became available in the early 21st century in the US and were widely accepted as a means of establishing genetic propensity to disease.

Method: The ethical implications of restricting DTC assay data to professionals and large research institutions were assessed with a review of literature over the last decade on direct-to-consumer assays and their relevant ethical issues.

Findings: Significant concerns are expressed about the methods that DTC assays are used as entertainment for relatively healthy individuals who also obtain ancestry data and some unusual phenotypic findings. The traditional modes of ethical care, beneficence, paternalism, concern for distributive justice, limited autonomy, all existed in the examination room where a period of credentialing and expertise was required before counseling was offered. Today, primary care practitioners are confronted by patients with DTC results whose significance and accuracy is not always established. Surveys of patients reported in *Annals of Internal Medicine* document that DTC findings show limited applicability to ongoing medical care (at least 20% of respondents who shared information with providers felt their doctors did not understand the results). Medical fact sheets for the public urge guidelines for better transparency and logical consistency. Other reviews emphasize the slanted bias toward benefits over risks in the commercial literature of DTC companies.

DTC companies have increasing potential public liability and their increasing governmental body restrictions have forced a merger with standard pharmacology companies. In a paper from Oxford in 2008, for example, 4 DTC companies were reviewed with respect to the spectrum of their public access and accountability. Today, only one of the described companies operates independently, the other being subsumed under larger, more regulated, clinical testing or pharmacologic companies. The fourth company moved some of its activities abroad. Other ethical issues involve distributive justice for disease, with some disease states with an inherent genetic basis not easily studied by DTC (e.g., Huntington disease carrier state). Finally, whole genome wide assays are now available from a limited number of companies, with undetermined ethical consequences.

Summary: DTC companies surfaced a decade ago in the US, and regulatory agencies were not available to restrict or contain the gambit of their actions. With US and European regulatory agencies limiting the scope of their actions, the companies now seek the umbrella of larger, more regulated agencies, consider moving divisions to less regulated nations, or significantly limit the spectrum of disease states and genetic findings offered. DTC offer a hope for much of the public to find an alternative, autonomous and cheap form of preventive medicine. The incomplete knowledge of such databases by the public is a real concern among professional bodies as is a risk for actual harm. Many professionals believe that when significant clinical findings with a genetic basis develop among patients or their family members, the medical consultation room with well-trained specialists remains the gold standard.

About multidisciplinary character of ethical problems in modern prosthetics

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Products of modern prosthetics in the terminology of engineer science are biotechnical systems (BTS). This is a special class of big systems, which technical and biological elements are combined in a single control loop for the achievement of the main function. In prosthetics, such systems are human – like objects, because they include a man, significant part of the biotechnical system. During formation and exploitation of such objects are remembered humanistic values, appear ethical problems and necessity to define the borders of possible intrusion into man's bio – psycho – physiological and social nature.

Prosthetics relates to medical – social technologies and because of that is an object for bioethical research, what is proved by themes of bioethical science forums of the last decade.

With that, technical nature of some elements in the biotechnical system “human – prosthesis” makes it a technoethical object. Determination of ethics in application, use and distribution of technical devices is an independent part of technoethics.

Engineer view at bioethical problems allows to state that the violation of general technical principles at use and exploitation of the prosthesis product/service leads in the end to serious bioethical problems. Firstly, this applies to such principles as: the principle of adequate conditions, the principle of a joint informational environment, the principle of stage modeling. Therefore, exploitation of the prosthesis product/service by the consumer is not reconciled with the mandatory usage conditions of the product. Moreover, engineer model of biological element BTS “human – prosthesis” does not include human bio – psycho – social characteristics; it is oriented to compensation of lost physiological functions.

Economical view at bioethical problems in prosthetics shows additional reasons of their appearance. Being a product/service of medial-social purpose, prosthetics need special comprehension in conditions of post – industrial society. In the post-industrial society, takes place the transformation of some basic institutions. Were created health institution, rehabilitation industry. If previously society refused

to help its members (medically, socially), now it offers such services. Service – product, an essential part of the market and industry. The market has own rules, quite ambiguous for the definition of its influence on society development in general.

If for the concept of help, such characteristic as standard is uncommon, because of its moral – ethical motivation, for the service the standard is one of the main characteristics. The emergence of standards marks the transition from individual to the mass product. What means that social systems of health care and social protection / rehabilitation are oriented on some general object from the huge mass. In market terms, the person turns into a collection of elements (body, a list of possible reaction and needs). Perspectives of humankind in such development conditions and transformations of the basic social institutions are at serious risk. Still, that industrial approach makes prosthetics economically affordable for the bigger part of human society.

The emergence of bioethical, technoethical and economical contradictions in such conditions is inevitable, it is impossible to solve them separately. For the transition to systematical solutions of such problems are needed multidisciplinary teams of experts and researchers.

From enhancement to correction of ‘evolutionary mistakes’

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Darwinian explanation of human disabilities is widely spread in popular biomedical literature. From evolutionary perspective, human beings are predisposed to heart attack and dorsopathies due to their anatomical features. Gary Marcus stresses the contingency of brain structure in the book *‘Kluge: The Haphazard Evolution of the Human Mind’*. Darwinian medicine underlines the inequality between ‘normal’, ‘reasonable’ and ‘natural’ in biomedicine. More reasonable engineering solutions are usually described by supporters of evolutionary medicine on the level of tissues and organ structures. But the molecular level remains an area of unpredictable effects and complex relationship between molecular signaling pathways. So there are no appropriate scientific arguments to judge about reasonability and ‘evolutionary mistakes’ on the molecular level as many mechanisms of regulation and interaction are not completely understood.

Many supporters of human enhancement technologies have enough biological knowledge, besides sociological data indicates increased use of cognitive enhancements by young medical

professionals. Therefore we can suppose that enhancement technologies have two lines of theming according to their epistemic ground. We propose to analyze expectations from the use of two types of enhancements: performance enhancements that are supposed to work on molecular level and implanted electronic devices that extend the functionality of any part of human organism. Both of enhancements types can work in the same sphere: in area of cognitive enhancement we can find widely used 'smart drugs' and projects of artificial neural networks embedded in brain. They have the same goal – to enhance brain operability, but they demonstrate different localizations of action, different epistemic ground, and placed in the different teleological context. Pharmaceutical performance enhancers are designed to make some existing function more strong through acting as molecular stimulus for work. These substances only modulate process of excitement and inhibition inherent in the brain. Artificial devices should correct the 'evolutionary mistakes' make human being less 'natural' but more 'reasonable': artificial retina shouldn't have blind-spot.

Despite the similarity of goals of these enhancements their dissemination can lead to separate social and humanitarian consequences. So consideration of goals is not enough to distinguish enhancement technology, such epistemic concepts as (un)predictability and contingency also can mark the imaginary plan of technology. The research is supported by Russian Science Foundation, project 15-18-30057.

Why women are not mentioned in the discussions about enhancing?

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This paper relates to a cultural tale in the Jewish tradition of two women, both queens. One is celebrated, the other is not. Could this tale explain - at least in part - why women are not mentioned in the discussions about enhancing? Are patriarchal values still ruling in the developed world in which women are supposed to still adhere or at least perform by these values? This paper focuses on new technological advances in genetics and reproduction, the role of women in a scenario of enhancing and finally, on the advent of the artificial womb. All of which are happening in a world in which abortion is still outlawed - or permitted with severe restrictions - in 80% of the countries around the world.

Rehabilitating nature? Naturalness and the naturalistic fallacy in mainstream bioethics

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Bioethics is concerned with novel processes and entities such as IVF, genetic modification of crops and animals, reproductive cloning and xenotransplantation. These developments allow us to change things that were previously beyond our control. Arguably, it is precisely the 'unnatural' that generates the *need* for bioethical enquiry. It is paradoxical that despite this, bioethics is so polarised with respect to the moral significance of the natural. Many influential bioethicists repudiate any suggestion that 'naturalness' can or should play a part in moral evaluations. The motives for the use of, or avoidance of, appeals to nature in bioethical reasoning, are coloured by an array of disciplinary, territorial, religious and political convictions.

At the most basic level, others may feel that it is morally wrong to alter, distort or subvert natural processes. Leon Kass, for example, argues that an intuitive recoiling from interventions such as cloning that distort or fragment the natural processes of reproduction, is

a powerful indicator that such interventions are unethical.^{Error! Bookmark not defined.} Yet seemingly, to talk explicitly of naturalness is to fall into a logical trap. Singer and Wells state categorically that "...there is no valid argument from 'unnatural' to 'wrong'".ⁱ Similar views can be found in the work of many bioethicists: "...stipulating that research is 'unnatural' says nothing about its ethics." Gregory Pence derides those who "...commit the *Evolved Implies Ought* fallacy which states that because human evolution to date involved practice X, therefore, practice X is moral."ⁱⁱ There are two ways in which this supposed fallacy can be understood. G.E. Moore's use of the term 'naturalistic fallacy' rests on the idea that terms such as 'good' or 'right' are not reducible to other properties.ⁱⁱⁱ Hume's is/ought distinction, on the other hand, refers to the habit of deriving a normative conclusion from a statement of fact. In bioethics, both Hume's and Moore's points are often conflated into a single term: the 'naturalistic fallacy'.^{iv}

In this paper I explore the ways in which concepts of the (un)natural feature in contemporary bioethical reasoning. I set out the ways in which concepts of nature feed implicitly into other aspects of bioethical discourse and consider ways in which the use of, or repudiation of, concepts of nature, are associated with specific epistemological or value-based standpoints. I ask whether we can refer to nature in any sensible way at all given John Stuart's Mill's complaint that nature means either everything there is, or everything apart from mankind. I suggest that we *can* refer to something as 'unnatural' if we construe the natural/unnatural divide as a spectrum rather than a clear boundary. In bioethics, the Millian question of scope is often conflated with the naturalistic fallacy itself. I show that when the two are separated, appeals to nature can be accommodated in bioethical argument provided that the terms 'natural' and 'unnatural' are not expected to *answer* moral questions, but are used to show *why* certain moral questions may arise.

ⁱ Singer P, Wells D. Ectogenesis. In Gelfand S, Shook JR, eds. Ectogenesis: artificial womb technology and the future of human reproduction. 9-26. Amsterdam: Rodopi. 2006

ⁱⁱ Pence G. What's so Good about Natural Motherhood? (In Praise of Unnatural Gestation). In Gelfand S, Shook JR, eds. Ectogenesis: Artificial womb technology and the future of human reproduction. Amsterdam: Rodopi. 2006. p78

ⁱⁱⁱ Moore GE. Principia Ethica. Cambridge: Cambridge University Press. 1993.

^{iv} De Vries R, Gordijn B. Empirical ethics and its alleged meta-ethical fallacies. Bioethics. 2009; 23(4): 193-201

Artificial organs and obsolescence

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Progress in medicine and material science has made possible an ever-expanding list of sophisticated medical implants and prostheses designed to improve patient functioning or extend life. Today, when parts of the human body wear out or are injured or otherwise cease to function it is often possible to replace them with an artificial version. The advent of 3-D printing technologies holds out the prospect of producing medical devices that are individually manufactured to suit their intended recipients. At some point in the not-too-distant future, it will be appropriate to describe some such implants and engineered tissues as "artificial organs". This paper discusses the implications of technological progress and network effects, which both separately and together may render particular artificial organs obsolete, for this project and for the ethics of transplanting artificial organs into patients. I argue that the possibility that individuals' organs will be rendered non-functional by technological developments subsequent to their implantation establishes a strong case for

robust regulation of artificial organs, in particular to try to ensure backwards compatibility of new technologies.

The brain in action: Brain-computer interfaces and human agency

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Brain-computer interfaces (BCIs) are technologies that link the brain and external devices. Their application has increased in recent years. For example, assistive BCIs enable paralyzed patients to communicate or control external devices and prostheses; rehabilitative BCIs are designed to facilitate recovery of neural functions. Not only do BCIs play an important role in medicine, they are also increasingly used outside of medical or therapeutic contexts (e.g., gaming or mental state monitoring). What is peculiar about BCI technology is that it seems to enable a way of acting that fundamentally differs from paradigmatic human actions. After all, the effects in the world come about via brain signals and need not involve any muscle movement at all. BCI-actions seem to have a *disembodied* character. So it does not come as a surprise that the use of BCI is sometimes described as “control by thought” (Bogue 2010).

Despite this apparent novel way of initiating changes in the environment and a vast philosophical literature on action and agency, a thorough analysis of BCIs in terms of action theory is lacking so far. In our paper, we seek to ameliorate this research gap and investigate BCI mediated action through the lens of action theory. We will delineate similarities and differences between paradigmatic bodily actions and events that are realized via BCIs, in order to expose peculiar features in need of further scrutiny. Further, we explore whether BCI-actions pose any challenges for our understanding of human actions and whether standard theories of action can help us to conceptualize the specific mode in which BCI technology enables people to cause changes in their environment. Our paper has merit for an ethical evaluation of the use of BCI technology, as actions are closely related to issues of autonomy and responsibility. To our knowledge, this is the first paper that specifically addresses the use of BCI technology in relation to questions of agency (as discussed in action theory) as well as subsequent ethical considerations.

The Need for Data to Inform Ethical Analyses of Novel HIV+ to HIV+ Organ Transplants

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Following passage of the HIV Organ Policy Equity (HOPE) Act lifting a federal ban on using HIV+ organs for transplantation the first HIV+ kidney and liver transplantations for HIV+ patients in the United States were performed at Johns Hopkins Hospital in March 2016. To date only a small number of HIV+/HIV+ transplants have been done globally, with most in South Africa and some in Europe. It is hypothesized that HIV+/HIV+ transplants will prove to be safe and effective, thereby providing a novel source of organs for people living with HIV who face high mortality on organ waitlists as well as alleviating the organ shortage more generally. However, the novel practice of HIV+/HIV+ transplantation raises substantial ethical issues that must be addressed for both recipients and donors related not only to access to organs, but also to risk and consent. For example, there are uncertain physical risks such as those associated with the use of immunosuppressive agents along with antiretroviral therapy and the possibility of HIV super-infection (secondary infection) with another, potentially drug-resistant strain of HIV. In addition, there are psychosocial risks related to having to choose between accepting an HIV+ organ with unknown risks or staying on an organ waitlist

awaiting one that is HIV-, which also pose challenges when obtaining informed consent under the time-pressures of deceased donor transplantation. Furthermore, while there are published requirements for the initial wave of HIV+/HIV+ transplants being conducted under the HOPE Act in the United States and standard clinical and research practices at individual institutions offer basic ethical protections, such as research ethics review and oversight, they are necessarily limited by lack of substantial experience conducting these novel transplants. It is simply unclear how well such approaches will protect and respect those offered and receiving HIV+ organ transplants.

Accordingly, there is a need to collect data to inform the ethical analysis of novel HIV+/HIV+ transplants. In addition to information about clinical and scientific outcomes of these transplants, data related to social and ethical domains are needed. For example, in-depth qualitative information from the early recipients of HIV+/HIV+ transplants as well as those patients living with HIV who are offered an HIV+ organ and refuse will be crucial to evaluating the quality of informed consent. Similarly, understanding the experiences of independent recipient advocates is important to be able to assess how this unique role contributes to the informed consent process. Further, data from patients living with HIV who are on an organ waitlist about their attitudes and beliefs about HIV+ transplants will facilitate assessments of the potential scalability of this approach should it be found to be safe and effective. Finally, eliciting the willingness of people living with HIV to donate organs will be essential to gauging the feasibility of this approach. In aggregate, mapping, navigating, and ultimately reconciling the ethical issues regarding HIV+/HIV+ transplantation in actual settings will be vital to ensuring that conceptual work is appropriately informed and that such transplants are responsibly and appropriately translated into clinical practice.

The phenomenology of brain death

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In what possible way could brain death be a phenomenological issue? If there is no activity going on in the brain there is hardly any experience to put to scrutiny either. Nevertheless, brain death patients appear from the second- and third-person perspective and from these points of view their condition raises many questions. The phenomenologist Hans Jonas argued in a paper published already in 1968 that the procedure of declaring patients lacking brain activity dead is nothing but the pure instrumentalization of their bodies (1987: chapter 10). This appears to be a harsh judgement considering the many lives saved by posthumous organ donation, but it should be pointed out that Jonas's wish and ethical claim was not that brain-dead patients should be kept on ventilators until their hearts spontaneously ceased beating. His claim was that we are not entitled to declare them dead – rather than letting them die – in order to be able to use their bodies as 'organ banks', as he puts it (Jonas 1987: 219). Jonas is not alone in criticizing the idea and definition of brain death for being incoherent and pragmatically rather than scientifically motivated (see DeGrazia 2005: chapter 4). There is no doubt something strange about claiming that patients with non-functioning brains who are kept on life (!) sustaining technology, and who in some cases have been witnessed to go through puberty, heal wounds, fight off diseases, and even gestate a baby, are dead. These bodies, indeed, appear to have survived the death of their brains. In the presentation I will put phenomenology in action to better understand the relationship that holds between a human body (organism) and the person that it in certain states of complexity makes possible. What can phenomenological analysis tell us about this relationship and the defining circumstances of persons going out of existence?

References:

DeGrazia, D. 2005. *Human Identity and Bioethics*. Cambridge Mass.: Cambridge University Press.
Jonas, H. 1987. *Technik, Medizin und Ethik*. Frankfurt am Main: Suhrkamp Verlag.

Time to rethink germline intervention issue in The Oviedo Convention

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This year we will celebrate the 20 anniversary of the European Convention on Human Rights and Biomedicine (The Oviedo Convention). The Oviedo Convention of 1997 is the first and so far the only international legally binding treaty which forbids any inheritable interventions in human genome (for those member states of the Council of Europe which signed it, ratified it, and implemented in national legislations). The position of absolute ban on germline modifications has been reaffirmed at the EU level by the Directive 2001/20/EC and more recently by the Regulation (EU) No 536/2014 on clinical trials. However, the recent very rapid development of precise genome editing technologies like CRISPR/Cas9, together with fast growing knowledge on genetic diseases and the recent Report of the international Committee on Human Gene Editing (NASEM 2017) question the ban of germline therapy as it is stated in the Article 13 of the Oviedo Convention.

For decades geneticists have followed the ethical rule “do not interfere with germline genes in humans“. And for a very good reason, which nobody understands better than geneticists themselves – it would be extremely irresponsible, to change the human germline with the technologies used for the creation of genetically modified organisms. In many countries a germline gene modification in humans is prohibited by national laws or by guidelines.

However, the long-lasting taboo of touching human germline was broken in 2015, even twice that year. First, in February 2015, by the decision of the British Parliament to change the law in order to allow fertility clinics to carry out mitochondrial donation techniques which alter maternal germline (note that The UK is not a signatory to the Oviedo Convention). Second, in April 2015, by the appearance of a publication written by Chinese scientists in which they described the first-ever experiment using CRISPR-Cas9 system for editing chromosomal germline genes in non-viable human embryos. The latter has provoked a world-wide avalanche of new discussions on the consequences brought about by the new technologies of genome editing, particularly by the CRISPR-Cas9 technology. The Council of Europe Committee on bioethics ([DH-BIO](#)) on its 8th meeting in Strasbourg on 2 December 2015 adopted a Statement on Genome Editing Technologies in which agreed to examine the ethical and legal challenges raised by genome editing technologies, and use the Oviedo Convention principles with the Article 13 as reference for the debate.

In the paper I will try to answer the question whether it is time to start thinking about new Article 13 of the Oviedo Convention, which would allow clinically safe germline gene therapies. In another words, whether safe germline gene therapy violates the fundamental principles of human rights and dignity on which the Oviedo Convention is built on.

Assistive technology, work and health: ethical issues

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“Assistive technology is any product or service designed to enable independence for disabled and older people”¹. Cathy Garner, Chair of the Fit for Work Coalition, has stated in relation to a Future of Assistive Technology conference: “If we can empower and support people with long-term conditions to remain in or return to work, individuals, employers, and society as a whole will all reap the rewards.”² Furthermore, it is said that “work is good for health”³, and that “the relationship between employment and health is close, enduring and multi-dimensional”⁴. So, there are good reasons to try to support disabled people into work, and if assistive technology can help achieve this, then this would be very positive.

However, in this paper, I aim to explore the downside of this approach, and particularly the ethical issues it may raise. What if, in spite of all possible assistive technology, an individual were still “unable” to work? Firstly, society expects some independent verification of this fact, so there is medicalisation of this process. Secondly, there is an expectation that the outcome is binary, that is, the doctor determines that the individual indeed can or cannot work. In practice, this is not always clear, and some of the difficulties will be described. Thirdly, those who are less able to access health enhancing work may also be disadvantaged more generally, so other social factors come into play.

There is then the danger that those who feel unable to work in spite of the resourcing of assistive technology, end up being blamed. For example, it might be suggested that they lack motivation, or that they are “free riders”. Ironically, as newer assistive technologies continue to improve, this problem may be highlighted even more. To mitigate this, I will propose that health is viewed through the lens of the “capabilities approach”⁵, and that everyone should be free to make their individual choices.

¹ UK Department of Health, Research and Development work relating to assistive technology 2014-15, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/446883/ass_tech_report_acc.pdf

² <http://www.salford.ac.uk/onecpd/courses/the-future-of-assistive-technology-summit-and-exhibition>

³ The Government’s Response to Dame Carol Black’s Review of the health of Britain’s working age population, *Improving health and work: Changing lives*. London:2008, p.22.

⁴ The Marmot Review, *Fair Society, Health Lives, Strategic Review of Health Inequalities in England post-2010*, 2010, at p.69. <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

⁵ Venkatapuram S. *Health Justice*. Cambridge:2011.

LVAD: is an ethical option for all patients with an end-stage cardiac disease?

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This work addresses ethical issues related to patients with a mechanical circulatory support (MCS), in particular left ventricular assist device (LVAD). In the ancient Greek thought the heart was considered the most important organ of the human body as the place of feelings, desires and memory. Nowadays, many words have a connection with the word “heart”, e.g. the Italian word “coraggio” and the English “courage” comes from ‘cor habeo’: ‘to have heart’, which refers to the idea of being brave. The idea of movement and vibration, which can be found in the ancient Greek ‘kardia’ and in the Latin ‘cor’.

This root recalls the idea of bending, turning around and pushing which draws attention to the energy of the cardiovascular system like the clinical situation that is present with this kind of device. The prevalence of heart failure (HF) is very high in the adult population, who can develop an end stage HF, MCS can be used to unload the failing ventricle. This medical-engineering field has made great progress in the past 15 years. The most incredible example of this rapid development is the technologic improvement of the permanent implantable LVAD. These devices are mechanical pumps connected to the pathologic-heart and can

replace the cardiac function. Newer generation LVAD are surgically implanted and connected via a cord to an external controller that extends out of the body. This is the real practical problem: the external controller must always be connected to an electrical power source, either an outlet or batteries that can be recharged through the skin or require an external power connection cord. These devices are used in patients who had acute but likely reversible HF, in patients awaiting donor hearts as a “bridge to transplant” and also are used as “destination therapy” for patients who are not candidates for heart transplantation.

In Italy there is the ITAMACS register coordinated by CNT (National Transplantation Centre) and the Veneto Region, which includes all types of long-term MCS that are performed in every national center. From 2010 to 2015 we registered 617 implants of these types of device. Patient selection for LVAD is crucial: the clinical point of view is fundamental, but not sufficient. It is also important to consider the ethical concerns related to device deactivation, the possible development of co-morbid conditions including major depression, caregiver burden, the need to regularly address changing goals of care and the experience of living with a foreign device that depends on a battery.

We intend to analyze how the selection of patients is made, to understand how nowadays these persons are taken care of and what is their follow-up. This will be pursued not only from a clinical perspective, but also from a broader ethical and psychological one. In collaboration with CNT and the centers network that have a LVAD program, we are recruiting patients and informal caregivers for a survey based on interviews on their experiences, with special focus on end-of-life decisions and communication among them and the healthcare providers.

The Organism-Machine Distinction: Implications for Bio-technology

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The successes of science and technology in understanding and manipulating the physical world have progressed on the assumption that it can be conceptualised as mechanistic. As a consequence, biology, in seeking to be scientific, has focused on identifying mechanisms operating within living beings. Medicine followed the same route in attempting to understand and control health, illness and disease. Human functioning is assumed to be explicated by mechanical processes.

Despite, or perhaps because of the great advances in understanding and practice that emanated from this approach only sporadic attempts have been made to reconcile a major difference that exists between the focus of medicine and the physical sciences. The living world entails organisms that are intrinsically purposive—self-regulating, self-maintaining and self-producing—while machines are extrinsically purposive—externally produced, directed and maintained—whether by conscious design or according to physical laws. Organisms, from the earliest stage of their existence, are whole organised entities, while mechanisms are formed from pre-existing parts.

Heidegger argues that: organisms “have a specific essential wholeness by virtue of the fact that they are organisms.” But what does ‘essential wholeness’ mean and what are the implications for medical bio-technology where machine parts and machine concepts underpin technological development as it is applied to enhance human behaviour.

This paper will highlight and begin to explore the fundamental differences there are between mechanisms/machines and organisms and the possible ethical and practical issues for biotechnological development that have so far been ignored.

Individuals and genomics: patient perspectives about sharing information with relatives after NGS testing

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We are conducting a focus group study with cancer patients about potential applications of next generation sequencing (NGS) technology. Our goal is to gather data on patients' perspectives to help build national guidelines about informed consent for NGS testing. One of the topics in the focus groups is the communication of results (medical professionals to the patient) and another topic is the communication of results to the patient's relatives. Our preliminary results indicate that many of the participants do not feel comfortable about medical professionals deciding for them which information is relevant and prefer full disclosure of results. However, when asked about sharing potential germ line mutations with their relatives, several participants feel that they should have the right to decide which results are shared. This finding is peculiar because sharing genomic data for scientific purposes or to benefit the treatment of future patients is not deemed problematic. This seems to indicate that participants value anonymity and confidentiality over the wellbeing of their relatives.

Our participants were thinking about genomic testing in individual terms. This is consistent with the default position in most guidelines, where patient information is described as confidential and disclosure of information is only allowed with explicit consent from the patient except when the potential harm to relatives is serious, imminent, foreseeable and likely. Several authors have suggested changing this default position to a joint account model of confidentiality, where genetic information is conceptualized as familial and information is shared unless other account holders choose to be excluded. We argue that it is important that genomic medicine is conceptualized as family medicine rather than individual medicine to relieve the ethical tension we encountered in our focus groups.

This conceptualization has important implications for informed consent for genomic testing, which should include a statement that relevant results will be used to inform the appropriate healthcare of family members.

New revolutions and evolutions in and around healthcare. Empowering patients or making them more vulnerable?

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Several revolutions and evolutions are reshaping health care. These revolutions and evolutions have a huge impact on patients. I present several of these phenomena and indicate what their desirable and undesirable impact can be for patients and medical doctors.

First, health care has become unimaginable without the integration of information technology (the Internet). The realization of the potential of this technology is perhaps the most important challenge of health care today. Obviously, it has beneficial effects. The Internet is beginning to change the exclusive focus of medicine from curing disease to prevention of disease. The Internet is also increasingly becoming a source of health information for consumers. It is used by more and more people to gather information and address their own health-related needs. It even has an impact on clinical trials. More and more patients gather information on their own about clinical trials and try to convince their physician to contact the pharmaceutical company or move to the medical setting where research subjects are included. Secondly, until recently

pharmaceutical companies had to rely on medical doctors to get patients enrolled as research subjects. Since a few years pharmaceutical companies are having direct access to patients/research subjects without the 'barrier' of the treating physician. Thirdly, this evolution is also stimulated by citizen science. Although the term has been defined in many ways, it broadly refers to the idea that research questions involving enormous data sets can be answered through online crowdsourcing. There is no shortage of scientific data. The problem is processing all that data. At first glance, citizen science seems like it could have huge potential outside of research and inside hospitals. It is possible to imagine using the power of crowdsourcing to find patterns in electronic medical records and to identify health trends. Fourthly, smart devices such as smartphones and tablet PCs have become an integral part of everyday life. This is also true for medicine.

At the same time, we should remain vigilant and sometimes skeptical about these new phenomena. One might worry that patients who turn to Web sites for information may not consult a doctor when serious health problems occur. What are the major factors that are leading to the increased use of the Internet by consumers to obtain health-related information? How do physicians view the use of the Internet by patients to obtain health-related information and services? How is the use of the Internet by consumers affecting physician-patient communication? What are the implications of the Internet for the future of physician-patient relationships? To enhance patient safety for medical apps or health apps that are to be used successfully in today's medical settings, shouldn't a good information policy not always be part of the marketing strategy? Citizen science in the area of astronomy is okay but in medicine? Do patients want the world looking at their health records? Do we want the treating physician to remain a gatekeeper between the patient and the 'outside' world?

Improving population health with innovation in Central Ohio, USA: One homeless patient at a time

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This presentation will explore how the now universally used ICD 10 coding system, adopted in the United States of America (USA) in October of 2015, is helping to improve health outcomes for homeless patients in Columbus, Ohio USA. This change along with parallel expansions of existing but previously scarce technology such as mobile medical vans is being combined with innovative technologies such as telepsychiatry to improve physical and mental health outcomes for homeless patients. This presentation will focus on the experience of health care systems in the capital city of Columbus Ohio, USA.

A paradigm shift in recent years towards broader consideration of homelessness as a key social determinant of health was facilitated by the transition to the ICD-10 system late in 2015. While the universal and exclusive use of the ICD-10 system was accomplished late the USA as compared to other countries, emerging technologies and changes in the health care delivery system can be attributed to its adoption. This classification system permits meaningful use data collection of patient homeless status. This mechanism for gathering this data, has allowed the American health care industry to identify those patients entering the system who are homeless and to more effectively address their complex medical needs in a number of innovative ways.

In general, those who are homeless disproportionately utilize emergency department services but generally lack access to on-going primary care services for chronic physical and mental health conditions. With the ability to code a patient as homeless early in a hospital stay the healthcare system has instituted mechanisms to more effectively meet the needs of the

homeless individual once discharged. Thus; previously established mechanisms which provide access to health care for non-traditional patients have been expanded such as the use of mobile medical vans and this data is also propelling development of emerging technologies such as innovative telepsychiatry. Once this data point is a part of the electronic medical record the patients services can be guided through compassionate and effective protocols designed to improve physical and mental functioning with the ultimate goal of reducing homelessness. Upon discharge from the hospital the patient will have access to ongoing physical and mental health care via mobile medical vans whose staff have parallel access to the hospital records for care and documentation. Additionally, the emerging technology of telepsychiatry can become part of the services offered to homeless patients. This emerging technology has its roots in the Veteran's Administration Services in the USA and it is being deployed to meet the prominent need which exists concomitant with a shortage of mental health providers to adequately address the service demand for this and other populations. There are several benefits for the homeless person and the healthcare system including that medical care is delivered regularly at or near the homeless camps by familiar staff which increases continuity of care for patients, care provided is more comprehensive and proactive which reduces emergency department admissions, and may ultimately assist in reducing individual homelessness and improve population health outcomes.

The precision medicine initiative as a health-data driven cosmology

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This paper analyses the 'All of Us' research program for collecting precision medicine data announced by NIH in October 2016. The objective of this cohort, based on quantitative risk estimates derived from genetic, lifestyle and environmental data (collected from a million or more Americans), is to facilitate "precision medicine" and to overcome the one-size-fits-all approach. The 'All of Us' program is an exemplification of data-intensive and patient-driven research. This paper looks at Precision Medicine as a new unique data-intensive *cosmology*, a concept developed by Jewson, because it involves transformations on the level of vocabularies, roles of patients and physicians and the concept of disease. Or, in terms of Michel Foucault, precision medicine involves transformations on three axes: on the axis of biomedical knowledge, of bio-medical power and of the self. Patients are encouraged to become the managers of their heir own health status, while the medical domain is framed as a data-sharing community, reflecting changing power relationships between providers and patients, producers and consumers. Considering illness as a manageable future event implies new responsibilities and fosters a molecularised conscience, based on individualized precision measurements, while according to critics the entrepreneurial logic involved may undermine humanistic values in the medical domain. I will conclude that the debate should focus on the issue of a healthy medical 'ecosystem'; which involves transparency about consent and meaningful ways to acquire and employ health data.

Reshaping the otherness in the context of the emerging technologies in healthcare

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In the context of the emerging technologies in healthcare, particularly when we consider the incredible opportunities offered by the technoscientific progress relying on the NBIC which

leads to the enhancement of the human being, it becomes more than interesting to reconsider our understanding of the Otherness of each human being. What does it mean to be the “Other” and does this understanding imply any consequences when it comes to the use of the new technologies.

**Nanomedicine and human health: When big questions arise from small technologies.
Current state of the art and future perspectives**

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The astonishing development of nanotechnologies during the last decades made a vast range of applications possible in almost every sector of our life, involving pharmacological research and human health. Several food packaging, clothes, cosmetics, electronic devices and even drugs already contain nanoparticles therefore everybody is now steadily exposed. Nanomedicine, i.e. the application of nanotechnology to medicine, aims to improve diagnosis, therapies and thus the prognosis of patients, with a reduction of time and costs. Nanomedicine is also leading to a revolutionary approach to disease management known as “theranostic”: the possibility to diagnose and treat the patient at the same time with a single drug administration. Despite encouraging results and interesting perspectives, nanomedicine applications could exacerbate serious issues, such as: dual-use, resource allocation, public involvement, environmental impact, human enhancement and human safety. Our team decided to focus on one in particular because it is the most worrisome: the human safety, consequent to the exposition to nanocomponents by field workers, consumers and patients. Our main concern is the lack of long-term toxicology studies, material safety data sheets and manufacturing processes specific for nanomaterials and thus raising serious questions about safety and efficacy of nanodrugs and nanocomponents.

In conclusion we think that the width, pervasiveness and uncertainty of these technologies impose to question current research protocols and laws from a scientific, legal and moral point of view. Our first goal is to analyse the current literature and to draw a comprehensive picture of the state of art regarding ethical reflection on nanomedicine, to expose crucial issues in research, development and marketing of novel drugs containing nanocomponents. Our second goal is an ethical reflection based on Beauchamp and Childress four principles of bioethics: beneficence, nonmaleficence, justice and autonomy. We will show if nanomedicine is taking into account those principles or not, with the aim to encourage a scientific development respectful to human health and dignity.

Participatory medicalization: How digital health transforms medical paternalism

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We currently witnessing a forceful movement towards the realization of a particular, technologically enabled vision for the future of biomedicine. This vision has many names, such as personalized medicine, digital health, precision medicine, P4 medicine, systems medicine, *in silico* medicine, eHealth, mHealth and quantified self. Its central promise is that computational modelling and analysis of genomic and other multi-level “big data” that is gathered continuously and often automatically about each individual will revolutionize medicine. A striking feature of the promotion of this vision is that we are promised not only better health and cost reductions through improved diagnostics, treatment, prediction and

prevention, but also more freedom and autonomy for patients. In what is often promoted as *participatory medicine*, the vision proposes a democratization of medical knowledge that empowers patients and enables a transition away from the paternalism of medical doctors. Everyone with a smart-phone gathering and processing personal health data is promised to be able to act as his/her own physician. Although a real potential for empowerment is acknowledged, it is here argued that the vision of participatory medicine as a freedom movement is unreliable. Instead it may be viewed as a form of self-medicalization or "*participatory medicalization*" with potential downsides. Other agendas than the freedom of citizens are evidently at work, such as professional, commercial and political interests, the aim of saving and making money, as well as the need for the data and cooperation of citizens in order to realize the future vision of a wellness culture. Education of and sensitization of citizens to the ideals of digital health and personalized medicine is envisioned as necessary, and in one sense, people's values and their agency itself is this sought medicalized. Crucially, the knowledge and definitional power in medicine is indeed transferred from medical doctors, but not primarily to patients or patient networks. Rather, the ability to handle the increasingly complex and non-transparent medical data and models are transferred to those who define, program and own the computational algorithms and metrics of health. The gaze of medicine is drawn further away from subjective illness narratives and symptomatic disease and towards computational "bio-narratives" of each citizen and the goal of detecting early disease and risk factors. This extreme focus on early disease detection increases the risk of overdiagnosis, waste and harm. At the same time, while responsibility for both individual and public health is given to individuals, it is unclear to what extent people are actually empowered to take control. These findings are discussed in light of concepts such as biomedicalization, biopolitics and technological paternalism. In conclusion, the promise of freedom in digital health and personalized medicine is ethically problematic as it may conceal vested interests and a potential for loss of freedom. When technological visionaries portray an unprecedented biomedical expansion into everyday life as "putting people first", it may be seen as an example of a new form of populism enabled by novel technologies, where new agents pit people against traditional experts.

Technologies and care relations; the special case of food care

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Patients, family caregivers and care professionals are confronted with technologies to improve or maintain the health or quality of life of patients or to improve the efficacy or (cost-) effectiveness of care. The perspectives of all stakeholders in a care situation determine how technologies will be used. In this study we discuss different perspectives on technology, health, food and care. Technologies may be regarded as deterministic or vice versa, individuals as fully autonomous in their use of technologies. In health care humans may be looked at as machines or as unique human beings. Non-health may be perceived as disease (naturalist, biomedical perspective), illness (normativist, subjective perspective) or sickness (constructivist, societal perspective) depending on the values and perspective of those involved. Similarly, each individual may have different perspectives with regard to food (as nutrition, as foods, as a diet, as eating, as an identity, as habit, etcetera). With respect to care the managerial, utilitarian perspective can be distinguished from the more fundamental, relational perspective. We highlight possible dilemmas with regard to a fair balance in care between patient, family caregiver and care professional, focusing on the special case of food care. Theory and practice show the importance of explicit thinking about one's own personal

perspectives on technology, health, food and care, and the possible perspectives of others. In conclusion, we pose that care (and food) professionals have a responsibility to be sensitive to and act on potential dilemmas in the use of technologies. Therefore philosophy of technology and healthcare should be included in the curricula of (para)medicine, nursing, and food programs as well as engineering and design programs.

Embodiment and prosthetics: Towards a more fine-grained account of bodily ownership

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Can we replace our hands? Recent developments in advanced prosthetics aim to incorporate nervous-system interfaces to provide quasi-sensory feedback to the user, as well as to enable control of the prosthetic. Although there are still technological barriers, prosthetics is coming closer to approximating natural functioning. In addition, there are reasons to think that prosthetics, like some other artefacts, can come to be regarded as expressive of their user's agency; and that some users 'identify' with their prosthetics in ways that are, in some respects, similar to the sense of identification people have with natural limbs.

This raises the question of whether, as prosthetics come to more closely approximate natural limbs, there necessarily remains a significant moral difference between natural and prosthetic limbs. To examine this question, I will focus on bodily ownership. Bodily ownership is often connected to the moral status of the body, with implications about rights over body parts and tissues. A difference between natural and prosthetic limbs in terms of ownership would thus imply a morally significant difference.

Bodily ownership is usually distinguished from property ownership, as it seems to refer to a sense in which one *is* one's body. This sense of being one's body is perhaps most usually understood to involve a relation of constitution between the self (the 'owner') and the body. But could one come to have a similar relation to a prosthetic? To answer this question, I seek to develop a more fine-grained account of what bodily self-constitution involves by introducing distinctions made by Paul Ricoeur about the nature of relations of 'mineness' or attribution, and drawing on some philosophical literature about embodiment. Using the resulting account, I argue that the sense in which one's limbs 'are' oneself can differ in both kind and degree, and that we may come to identify with material objects in ways that are potentially just as affectively and agentially compelling, and as complex, as is identification with our bodies. This could imply a deflationary view of the difference between natural and prosthetic limbs.

I conclude by noting some limitations with this argument as it stands, given ways that prosthetic self-constitution are still likely to differ from self-constitution with natural limbs. A subsidiary motivation for the paper, however, is to demonstrate the relevance of more fine-grained accounts of bodily ownership for addressing questions in bioethics.

The future of General Practitioners facing new technologies

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Considering that GPs are closer than other physicians to their patient's lived experience, we will organize very soon some focus groups based on the assumption that in the era of the quantified self, GPs either are in charge of providing a meaning to numbers or to vanish in the network ocean. Therefore we will discuss four topics in the frame of the focus groups:

- Evolution of the profession with preventive and decisional algorithms (i.e. GP replaced by technology?)
- Diagnosis based on cerebral imaging replacing clinical phenomenology (i.e. patient replaced by numbers?)
- The augmented GP and modification of clinical competencies (i.e. enhanced GP?)
- The use of biological sensors (i.e. enhanced patient?)

Our presentation aims to discuss opinions and attitudes of General Practitioners facing new technologies in their everyday practice, as they will be expressed during the focus groups. It should allow us to point out new professional identity, philosophy, and values. The discussion between an anthropologist and a GP should put in perspectives the opinions of GPs for the future and the remaining enigma of health (Gadamer).

Physicians' communication patterns for motivating rectal cancer patients to biomarker research participation: Empirical insights and ethical issues

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Background: In clinical research – whether it is pharmaceutical, genetic or biomarker research – it is important to protect research participants from abuse, to respect their autonomy and to ensure their control over health-related issues.

Communication processes are highly relevant to recruitment for research purposes for which also the physician-patient relationship plays an essential role. Some studies have shown that a trusting physician-patient relationship, in which a patient refers to a physician's reputation, is very important to patients when consenting to clinical research studies. This is why it is relevant to better understand which kind of physician-patient relationship (according to Emanuel & Emanuel 1992) is preferred by individual patients. With all relationships the underlying condition is good communication. Therefore, a closer look at the communication processes becomes necessary to improve mechanisms of recruitment in the clinical context.

Our aim is to identify communication patterns used by physicians to motivate patients to participate in clinical research and to assess whether patients also use these patterns in formulating their own research motivation.

Methods: We conducted an empirical-ethical research project with physicians and rectal cancer patients. We observed the initial clinical physician-patient consultation (n=54) and conducted three semi-structured interviews with each patient (n=40).

Results: Our observations show that the consent procedure for treatment and research study participation were clearly marked by formalized practices and strong institutional regulations. Consenting to the biomarker study thus constitutes a constantly repeating act. Patients mainly perceived the informed consent consultation as a standard procedure in which the signing of the consent form entailed the character of being non-negotiable. Other patients perceived the process as a form of legal safeguarding in the case of medical misconduct and possible inflicted risks.

In the observation of the consultations, we found two dominant communication patterns, which physicians applied for motivating patients to take part in a research study; here, we can differentiate between a *reputation* and a *reciprocity* pattern. Some forms of these patterns tend to mislead patients' understanding, while others could justifiably be applied in this consultation setting without undermining patients' autonomy. We found that patients can very well recall the content of the consultations even during extremely taxing cancer treatment,

which makes it even more important to strengthen the communication regarding research participation.

Conclusions: The different communication patterns should be examined more closely, also with regard to other clinical contexts. In this context, it would be important to encourage those communication patterns which are ethically acceptable and which could be deliberately implemented to enhance the communication of research aims. Parallel to considering physician-patient communication, we also need a more critical reflection of the ethics committee's requirements for information regarding research participation.

Ethical challenges in applying crowd science to research with human beings

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Crowd Science has become a prevalent platform for collecting information from and by all willing members of the public, enabling those interested in joining specific research projects to participate in the research by collecting and contributing information. These platforms offer a new research methodology using the internet to collect large quantities of varied information from diverse communities enabling the involvement of the researched communities, improving evidence and possibly reducing costs. Big data analysis maintains the integrity of the research, while retaining the potential for using the information for further research in the future. Though the popularity and usage of CS is increasing, we have not seen, until now, a comprehensive discussion on the ethical implications of collecting, augmenting and analyzing the data collected in this framework.

During the last two years, two think tanks have been working in the Technion- Israel Institute of Technology, in an effort to develop a crowd science infrastructure for academic research in a variety of fields including health, education, environment and inter-disciplinary research. One group has been working on the technologic infrastructure of the crowd science platform. The second group, which the authors are members of, is the ethics committee for the platform. The ethics committee developed a comprehensive ethical set of guidelines, for the operation of the crowd science platform of the Technion.

This presentation will address the dilemmas that we have encountered during the evaluation of ethical CS in general and CS involving human research subjects in particular. The ethical framework and guidelines for the platform will be presented as well as the variety of issues we addressed, including: privacy challenges, application of the principles of justice, reciprocity, accessibility to diverse populations (age, minorities, socio-economic background and more) and the ownership of the database. Special emphasis will be given to issues such as adjusted informed consent and voluntariness, as well as the required checks and balances among the different ethical principles.

Human enhancement as an object of bioethical reflection

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Bioethics can be considered as a specific kind of *reflection* on medical practice, in particularly on various (first of all based on biomedical technologies) goal-directed interventions into the human organism and psyche. Bioethical reflection in this sphere is aimed at search of matching between moral experience, intuitions, and deliberations of different individuals and

social groups, on one side, and swiftly growing opportunities for biotechnological impacts on them, on the other side.

In a social sense such reflection is needed for bringing to light and clarifying interests of different stakeholders involved in the development and use of a new biomedical technology and for reconciling these interests. Such bioethical reflection opens up opportunities for norm-substantiating and norm-establishing activities, hence for ethical and legal regulation of interactions among people in many complex real-life situations generated by such technologies.

During recent decades this reflection became an *institutionalized* form of response on many challenges in the field of human therapy generated by new biomedical technologies. That means that now it is a well-established practice, holding a definite position in the field, so that with regard to any new biomedical technology we need not to wait for some risky or negative consequences of its use before starting its ethical appraisal. More than that, rather often bioethical reflection from the very beginning is built in the processes of creation and development of such technologies as their necessary constituent. Many meetings, discussions and statements with regard to moral issues of gene-editing technologies represent the closest example of such reflective activity. So, bioethical reflection became an important aspect of social acceptance and adoption of new technologies in the field of human therapy.

Nowadays we can see that biomedical technologies are more and more often used beyond the field of therapy proper, for the sake of human *enhancement*. We are witnessing many discussions about interrelations between therapy and enhancement; some authors propose to make no distinctions between these two concepts at all. To my opinion, however, this distinction is rather important. Its importance grows, among other things, from the fact that the field of human therapy in general is much more institutionalized than the field of human enhancement. In the first one we have a more or less definite set of stakeholders having more or less definite interests. There is no such definiteness in the latter case, where neither potential set of stakeholders nor specific interests of every one of them are yet clearly ascertained.

Correspondingly, bioethical reflection directed to the technologies of human enhancement is far from institutionalized. So, we have neither enough analytical and conceptual means nor enough legitimized moral practices to make sound appraisals and decisions for different categories of human enhancement. Moreover, up to now we don't even have more or less generally approved classifications of such categories. That does not mean that bioethical reflection on issues of human enhancement is something futile. On the contrary, it means that such reflection is badly needed.

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Enhancing consent

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Various debates surrounding informed consent and its role are among the most prevalent within the field of bioethics. More recently there have been heated debates between prominent bioethicists over human enhancement. These have been propelled forward by the rapid progress of neuroscience (including psychopharmacology and various direct interventions in central nervous system). Within these debates consent to these enhancing interventions, possible undue inducements and social pressures have been extensively discussed.

In my presentation I would like to consider the opposite aspect that has been so far relatively neglected. It is the issue of how the new possibilities of human enhancement can affect our approach to consent, our understanding of competence threshold for some decisions, and our understanding of the decisional status of the patients. The creation of supra-persons could, at least in principle, relatively soon become a problem in health care as physicians (such as surgeons) are commonly postulated as targets of such enhancing interventions similarly to groups of potential enhanced patients such as soldiers or fire fighters.

In my talk I would test existing normative frameworks to find out if they are future-proof in this respect. The questions that require answering concern relationship of the *reasonable person* and *reasonable physician* standards and human enhancement; the relationship of consent procedures and information and enhanced persons; and last but not least the relationship of *cognitive* and *moral enhancement* and voluntariness of decision making. To make this project less of a pure philosophical exercise and keep some practical relevance for today I shall look for possible implications for the existing frameworks from this “stress-test”.

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The face of bioethics in international law: The case of human reproductive cloning

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The birth of Dolly the sheep two decades ago, following the emergence of the technology of reproductive cloning, led to a heated debate over the ethical, moral, and legal issues involved in the process. With the prospect of applying the cloning technology to *humans*, at the beginning of the second millennium, the mere possibility of successful human reproductive cloning (HRC) has generated even greater controversy and has been discussed in many settings.

Given the safety issues inherent to the technology, the uncertainty about its implications, and its possible global effects, international law played a major role in those discussions. For example, an early ban on HRC was regulated using couple of instruments of international law. The first is the 1997 Universal Declaration on the Human Genome and Human Rights, and the second is the 2001 Council of Europe Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being. The ban was justified on the basis of HRC being an affront to human dignity. More recently, the continued public debate over HRC led some bioethicists to introduce other regulatory models to control the technology, while others wholeheartedly advocated for an absolute ban. Still to date, significant policy and practical challenges remain for bioethics and bio law scholars regarding the conceptual and legal instruments that ought to ground the regulation or absolute prohibition of HRC.

The goal of this paper is to examine the suitability of application of international criminal law for the regulation of HRC. More specifically, it aims to propose an alternative instrument for the regulation of HRC through the model of Common Heritage of Mankind (CHM). To ground the practice of HRC in the relevant context, I will start by a brief review of its possible harms and benefits. Based on two assumptions; first, that HRC ought to be regulated and second, that the framework of international law is suitable for that purpose, I will focus on two specific models drawing on international criminal law: The first model relies on the doctrine of crimes against humanity while the second introduces a crime against humanity of a certain kind; that is a crime against humanness. Following this discussion, I will explore whether the precautionary principle, often invoked for the regulation of new technologies,

may provide an analysis firm enough to ground the regulation of HRC. Then, I will offer an alternative instrument of international law, the doctrine of Duty Based Common Heritage, and present its possible application for the regulation of HRC. I will conclude by arguing that this third model is more suitable than both the crime against humanity and the crime against humanness models for the regulation of HRC.

Rewriting genomes: from gene editing to the synthetic cell: A Teilhardian assessment

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Current emerging developments in post-genomics such as CRISPR gene editing reinforce the view that life is technologically reproducible and makeable. The ultimate goal is the production of a synthetic cell (the telos of synthetic biology), an event which also would have an ontological significance, for (according to advocates) it would demonstrate that we now really know what life *is* in a very fundamental way, and that there no longer is any principle difference between the laboratories of nature (where a plethora of life forms emerged in the course of evolution) and life sciences laboratories (where neo-life is produced). These developments trigger mixed (ambivalent) responses of fascination and unease, in secular as well as in religiously inspired bioethical discourse. In my paper I will argue that the view of Teilhard de Chardin entail crucial ingredients for a philosophical and bioethical diagnostics of the techno-scientific present. On the one hand, he argues that these developments (gene editing, the synthetic cell) are inevitable, as in human beings, evolution becomes conscious of itself, so that the future of life will be redirected by absorbing the biosphere (i.e. living nature, the product of evolution) into the noosphere (i.e. the global networks of knowledge, information, computers, laboratories, research consortia, infrastructures, etc.). At the same time, Teilhard argues, we experience a fundamental anguish in the face of the enormous responsibilities, which are opening up in front of us. Somehow, this uneasiness must be transformed into collective, global and distributed forms of scientific, philosophical and ethical reflection. CRISPR and the synthetic cell will serve as case studies to demonstrate the relevance of Teilhard's input for a global bio-philosophy / bioethics.

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