BIOETHICS AND BIOPOLITICS

PROCEEDINGS

OF THE 28TH EUROPEAN CONFERENCE ON PHILOSOPHY OF MEDICINE AND HEALTH CARE

Organised by:

The European Society for Philosophy of Medicine and Health Care (ESPMH)

Department of Behavioural Sciences,
Faculty of Public Health,
University of Debrecen

27 – 30 August 2014
DEBRECEN, HUNGARY

Proceedings of the 28th European Conference on Philosophy of Medicine and Health Care: Bioethics and Biopolitics

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ISBN: 978-963-473-728-5

Published by: Department of Behavioral Sciences, Faculty of Public Health, University of Debrecen

supported by TÁMOP 4.2.2.A-11/1/KONV-2012-0031 (IGEN-Hungarian) project IGEN1

PREFACE:

The organizers of the 28th Conference of the ESPMH invited presentations and plenary talks to focus on bioethics and biopolitics. The term 'biopolitics' is either used as a philosophical or sociological term referring to the works of Negri, Agamben, Rose, or especially to Foucault, who focused on the contemporary style of governing populations through bio-power, or as an umbrella concept referring to public policies regarding applications of biotechnology and the life sciences.

These usages suggest, that bio-politics is a central concept for modern societies. At the same time bioethics has become increasingly interdisciplinary and ever more politicized. Bioethical issues figure in presidential campaigns and parliamentary elections. Bioethicists are advisors for governments and frame recommendations for public policies. Bioethics and bio-politics have become deeply interwoven activities.

If bioethics and bio-politics are highly interwoven, then how should we understand their relationship? Does politics

corrupt bioethics? How does bioethics affect policy-making? How has bioethics been affected by its role in policy-making?

The invitation to reflect on these concepts and issues, to assess their relationship was successful as more than a hundred scholars sent the result of their intellectual efforts. The proceedings contain the abstracts of these presentations. The collected material provides the reader with a rich diversity of theoretical perspectives and empirical insights where bioethics meets biopolitics.

Editors

August 2014.

Hungary, Debrecen

PLENARIES:

Biopolitics and Biopower. The Foucauldian Heritage in the Light of the Contemporary Usage

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The notions of "biopolitics" and "biopower" enjoy a commonsensical plausibility in many fields of humanities today. From philosophy and sociology through cultural and gender studies up to various forms of contemporary political thinking, these notions are used and reused in many descriptive and normative approaches. However, even if it is often highlighted that the work of the French historian and social theorist, Michel Foucault served as a cornerstone in attaching the prefix 'bio' to the words 'politics' and 'power', the question as to for what reasons these terms, designed originally for historical research in Foucault, could reach such an interdisciplinary popularity remains to be worth studying. With this context in mind, this paper has two objectives. On the one hand, it seeks to reconstruct the meanings and roles of the notions of biopolitics and biopower as they are displayed in Foucault's historical and theoretical researches. On the other hand, it aims to foreground the theoretical significance as well as the descriptive and normative values that could be associated to these

notions in various fields of humanities within the contemporary conjuncture of biopolitical thinking.

How to get plump, or why do we choose what we choose?

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Back in the late 1800s advertisements were made for a dietary supplement called Fat-ten-U food, which guaranteed to "make the thin plump and rosy with honest fleshiness of form". By the beginning of the 21st century, an international company called Prescan illustrates its website with witnesses from celebrities to seduce us for a total body scan which "allows you to gain insight into your health. During this examination the vital organs and blood vessels are examined. In order to obtain the best possible picture of your body, we include the Preventive Cardio Package with our Total Body Scan."

In between these two remarkable ads, the health discourse has changed dramatically. Fitness and no longer fatness is the objective and the pressure to live our lives along certain patterns and paths is unmistakably high. The interesting thing is, there is no Uncle Sam pointing his finger at us, and yet, in one way or another, we agree there is something wrong with us if we don't care for our health and body or we plead guilty if we don't do any kind of physical activity.

With concepts like ‘governmentality’, ‘pastoral power’ or ‘population’, in his later lectures on biopolitics, Michel Foucault attempted to conceive the question how the care for public health became indeed a central task and for politics and for all of us. Health is not only on the political agenda of many governments (governmentality), it’s presence runs as an bioimperative through the whole of society. It appeals to all of us (a totalizing technique) and to each one of us (individualized). There is obviously something wrong with us (pastoral power) if we don’t obey the imperative.

I apply his analysis to the contemporary discourse on health promotion, the growing interest of the government and insurance companies in our daily activities and their attempt to interfere in it. Analysing the case of obesity, I will explore how the discourse on patient empowerment is actually the ethico-medical way through which people are governed. Far from a neutral plead, patient empowerment puts the individual responsibility for our health right at the centre of today’s medical discourse. Being unhealthy has become the synonym for not having done enough.

It is therefore no coincidence that today, public health, especially in industrialised countries, has also become a question of having no longer access to the health insurance due to ‘bad behaviour’, of being excluded from health facilities, of food industry trying to get a grip on our food habits and tastes with food supplements, etcetera. What we are dealing with today – public health as an explicit task of

contemporary politics – not only can be understood as the culmination of an ongoing process of government of our daily life out of a medical perspective; it is also an explicit political evolution which needs to be made explicit, in order to understand the biopolitical ideology behind it.

The "ME MOLECULE"

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It is inevitable that the discourse of biology is taken into account in the social sciences. And whenever a new biological or biomedical discipline emerges and promises to provide new answers to old problems, such as the role of biological factors in influencing health and behavior, scientists, policymakers, and the society as a whole tend to overestimate the significance of the new findings.

In my presentation I will focus on human rights as the catalyst and synthetizing force in these debates. Human rights, providing rights to the persons are now extended with open boundaries, such as rights related to human tissues, to human DNA, to brain-dead persons, and to *in vitro* embryos. Among the many interactions between the biological and the social I will turn my attention to a trend in which life itself has become an object of biomedical intervention, or, has

Hardt and Negri put it, “biopolitical production”. As it follows law reuses and reinterprets the notion of “human” on the *molecular* rather than on the molar level. As biological substances have increasingly become objects of regulation and natural processes are increasingly commercialized in other to scrutinize these trends, I will focus on human rights on the “cellular level” and introduce the notion of ‘*me molecule’*.

What happens, for instance, when one interprets discrimination based on genetic characteristics (on molecular level) or develops the notion of privacy based on genetics or neuroscience? Do these concepts follow from biopolitics, or are they just extension of a human rights category? What are the advantages and disadvantages of using a human rights framework on this level? The presentation will analyze the role of contemporary biopolitics through the lenses of human rights.

Controlling the psyche (The ‘psy-complex’ and its discontents)

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After the death of the soul and the birth of psyche, some new disciplines emerged viz. psychology, psychiatry, psychotherapy etc. This newly-born psyche has a congenital ‘disorder’: ‘The justification

of psychology lies in the fact that it acknowledged something noncorporeal, and its limitation lies in the fact that it wanted to determine it [noncorporeal reality] with the method of physical research—[with the method] of natural science. The justification of psychology consists only in its point of departure and in its taking the noncorporeal seriously. But then its justification already ends because it researches this noncorporeal with inappropriate methods. It is a justification turned into something unjustified.' (M. Heidegger). It seems that this constitutional problem has long lasting consequences for the cultural and scientific role of the psyche:

a) the mainstream method of the contemporary psychological researches, i.e. quantitative statistical analysis, seems to be only a hypothesis without any definitive proof; there are signs that the 'scientific' development of psychology has not been following a genuine route on an inherent logic of the discipline but an 'artificial' one which is based on the requirements of scientific acceptance and acquiring research grants.

b) psychotherapies were not able to prove their practices as technically based ones; instead they seem to be human endeavors which cannot be researched properly by sciences and the technics they use are not the main vehicles of their efficacy, the Dodo bird hypothesis or verdict argues that there are no significant differences concerning the effect sizes between different psychotherapies. It means that what really works in psychotherapies is something not technical.

c) psychiatry not only has a very controversial nosological system (DSM), but its state of the art somatic treatment methods (pills) are tending to be more harmful than beneficial for the patients/customers. The 'neuropsychiatric' turn can be a suicidal movement for the discipline itself because the ruling belief system and its rituals - expressing that the brain is the main target of research and treatments of mental problems - will finally convert psychiatry into neurology without leaving any place for its own identity. Attitudes towards psychiatry move between two end-points: anti-psychiatry: mental illness does not exist and neuropsychiatry: only brain diseases exist. Both means that psychiatry is in an 'eternal' existential crisis.

All in all, the modern project of controlling the psyche with methods and technologies provided by sciences has been keeping these disciplines in a controversial status without able to secure their position in our culture.

(Bio)ethical and (bio)political questions of measuring scholarly performance

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There is no more reliable way to assess a scholar's scientific output than to read carefully all or a selected set of her published

papers/books and evaluate her on the basis of their quality. This is, however, a formidable task, especially, when many scholars must be compared. Thus, instead of this time consuming method, a researcher is mostly evaluated today by using quantified surrogates of her scholarly output. The number of articles she has published, the cumulative impact factor of all the journals, in which her articles have been published, the number of citations her papers received, and many other metrics are designed to express in numbers the scholar's influence on her peers. Bibliometrics is increasingly used to ground decisions of promotion and tenure, to hire faculty or to award grants to research groups. This affects not only individual researchers, but whole academic institutions, departments, universities and other research units, which are also ranked on the basis of various citation based metrics they produce.

Using metrics to measure scholarly performance in a scientifically reliable way would be of outmost importance, because many important decisions are based on the results of these measurements. In spite of its importance, however, the measurement of scholarly performance is filled with poorly defined concepts, methods that are used in a manifestly discriminating way, and conceptual vagueness. Authorship is clearly one of the key concepts in research evaluations. It was, however, surprisingly late that clear criteria of authorship have been established, and little effort has been made to enforce their use in practice. This is a serious problem, because as false banknotes can

cause havoc in economy, inappropriate authorship can inflate the real ones and can make the reliable assessment of scholarly performance impossible. This is all the more important, because the number of authors per paper has steadily been increasing in the last decades, and today multi-author articles are the norm. Although today there are widely accepted criteria of authorship in biomedical research, but these criteria are often unknown or disregarded. The consequence is that a significant proportion of authorship lists can be regarded as misleading. Today it is almost impossible for an outsider to know what is the degree of contribution of each contributor to a paper or who were real contributors at all. Only those, who directly participated in the study, may know it.

The concept of contributorship, introduced in 1997, somewhat improved this situation, but it did not require the numeric expression of one's contribution to a paper publicly, so even now it is hard to use it as an assessment tool.

The lecture tries to analyse the causes of this situation and takes advantage of both the conceptual tools of biopolitical writers, and those of the French sociologist, Pierre Bourdieu. This helps to understand, how this discriminating system of scholarly evaluation could survive in a scientific atmosphere, where sophisticated mechanisms exist to eliminate even the slightest statistical bias from empirical science.

PARALLEL SESSIONS:

Frontiers of placebo surgery - bioethical questions and concerns of an innovative treatment method in psychiatry

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The use of placebo has been always a problematic issue among medical experts with a fully biological approach, and among those patients, who take the technological aspects of medicine too seriously. The need for clarification, what is placebo and what is not, is a streaming need in everyday scientific research, because the use of placebos is the gold standard when testing medical therapy. Although the idea of placebo surgery is known since the 1930's, only a few trials were conducted worldwide. Since the results of sham surgery and real operation can sometimes be significantly alike, the power of placebo effect during the fake intervention should be taken into consideration much more seriously. Indeed, examining sham surgery from a very specific angle may help an observer to identify new aspects of the placebo effect. This presentation aims to offer new avenues for reflection by telling a case history of a placebo intervention performed on a psychiatric patient. Using placebo surgery in psychiatry raises several ethical questions but it has not been attracting discussion until

this moment among the ethicists. The partial success of this case might be an initiation for further thinking to work out standards for a semi-assisted non-invasive psychodrama, as the procedure was named. Reducing mental symptoms via placebo effect does not share new insights, as is it a common experience in clinical practice. The novelty of this case is that it happened theoretically on the borderlands of two different approaches: the highly technical evidence based one and the commonly tacitly most rejected field of the 'existence based' placebo effect. The Declaration of Helsinki addresses the tasks someone has when using an innovative form of therapy. Psychiatry is still suffering from shadows of misusing lobotomy, insulin coma and electroconvulsive therapy in the past. Although bioethicists are not really open to share sham surgery practices, a well-established explanation of this kind of procedure may give a useful tool into the hands of psychiatric experts facing patients who are resistant to classical therapy. An in-depth theoretical analysis could shed light on the background mechanisms of sham surgery. The psychodramatic explanation highlights more underlying forces. Putting a patient into a dramatized situation, where he/she is playing a specific role, would expose him/her to harmful psychic rebounds or even to some physical impairments representing nocebo effect. What if the patient regains his/her normal mental functions after a sham surgery and reclaims the previously lost capabilities? Who is responsible for the documentation of a sham surgery or is it even possible to find a legislation regulating

such a procedure? Opening a discourse about such questions should help sham surgery to become a valuable therapeutic regime in psychiatry.

Bioethics, Politics, and Social Responsibility for Health and Well-being

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This paper concerns the conceptions of individual and social responsibility for personal health and well-being in bioethics and public health policy. The potential relation between bioethics and policy-making is discussed.

As reviews of the past and present bioethics show, bioethics has, or at least has had, a strong commitment to emphasize individual matters such as autonomy, at the expense of social issues. Despite the expanding amount of literature focusing on the social determinants of health, the individualistic approach relating issues of increasing health and well-being predominantly to matters of, for example, genetic enhancement, personalized medicine or mere access to health-care, is considerable.

This orientation reflects the way in which public policies increasingly focus on the individual. Recent studies on social policy documents

report a growing tendency of "responsibilisation" considering the individual as the most important target for intervention, assuming citizens as "expert patients" or consumers able to manage their own lifestyle and exercise choices responsibly so as to promote their own health and well-being, and consequently, as agents who can and should be held responsible for their health outcomes. Although the division of responsibility between the individual and the social is not a matter of either-or, the tendency of responsibilisation does not give an adequate account to the social determinants of health that can be affected by social policy decisions. The notions of control and personal responsibility in public policy seem incompatible with the social sciences and public health literature focusing on the fact that there are limits to individual responsibility due to environmental factors, including ecological, physical, social and societal issues, as well as epigenetics that affect a person's health, well-being, and her ability to control her own life and make genuine choices.

Even though bioethics as an academic discipline ought not to drown into politics, it is a fact that interdisciplinary bioethicists are currently a part of politics and this involvement entails great responsibility. As Albert R. Jonsen[1] demands, bioethics as a discipline and discourse has work to do in integrating the principle of social responsibility into its teaching and talking. If the discourse of bioethics had a stronger principle of social responsibility, could the public policy discourse be made more compatible with research on social determinants of health?

As a conclusion, I suggest that a stronger principle of social responsibility ought to be implemented in bioethics, for example, by relating questions of individual level to social contexts and social theory. This reinforcement would serve both the validity of bioethics as an academic discipline, and the constructive potential of bioethics as a discourse involved in politics.

[1] Jonsen, A. R. (2001). Social responsibilities of bioethics. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 78*(1), 21-28.

Biopolitics and the Longevity of Lefthanders

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One aspect of Foucault's concept of biopolitics concerns how society manages or governs certain groups of people, in particular when that sort of governance requires scientific knowledge about the group or kind of people in question. Lefthanders are one example of a kind of people that has to be studied and managed. In the early 20th century, left-handedness among school children was perceived as a growing problem. Not only parents, but teachers and school principals had to deal with this problem and they called upon scientists to give them more knowledge about these problematic children. Since then there

has been no end to research on lefthanders, in particular in psychology and health sciences. I will discuss one such case, a series of studies aimed at answering the question whether lefthanders die on average younger than right-handers. My discussion of these studies reveals how problematic the scientific definition of left-handedness is and also what effects (what Foucault termed power-effects) this sort of research has on its subjects. Although there is nowadays less pressure in the school system to manage left-handed children, the production of knowledge about lefthanders continues. I look at how this knowledge is diffused through scientific literature, popular science literature and mass media; and how these studies have given rise to confrontation and conflict.

Biological or Democratic Citizenship?

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There is considerable social science literature about active citizen participation in the shaping of public policy about science and technology. Some authors are rather cynical about dominant models of public engagement since they may reinforce existing power relations. The paper discusses Rose's and Novas' notion of biological citizenship which exemplifies a rich sociological analysis of how

developments in biotechnology are shaping contemporary citizens. Their analysis is largely framed in a discourse of production and marketing strategies of economy and biology where the vitality of citizens is harnessed for the promise of creating health and wealth. This description is critically evaluated and argued that while it is in many ways realistic, it ignores a normative dimension implicit in the notions of scientific literacy and citizenship. It is also argued that it is important to complement Rose's and Novas' analysis by a guiding vision of citizenship from the viewpoint of deliberative democracy. Sociological studies have shown that attempts to engage citizens in dialogues about public policy are faced with many practical difficulties and can lead to premature justification of emerging technology. This view can be easily substantiated with empirical examples, which show how people take part in the economy of hope engendered by the promissory science of genetics. As such it serves as a constant reminder of the processes of social engineering at work in democratic society, even in the name of public engagement and consultation. A neglected aspect of deliberative democratic theory in this context is its emphasis on legitimacy and accountability of public decisions. This implies that the focus needs to be more on the quality of the institutions and governance as conditions for democratic legitimacy than on active participation or pervasive public engagement. These two approaches are not to be reconciled because their value consists in the tension between them and the mutual

critical resistance that they provide to one-sided analyses of complex phenomena. The example of the Icelandic health sector database project is used to demonstrate how both these visions of citizenship can be relevant in an actual public policy.

Government, Big Pharma and the Exercise of Biopower: The ethical acceptability of lobbying and promotion

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Pharmaceutical medicines are routinely treated as commodities in the market-driven modern world. As such, the cost of healthcare is highly susceptible to the influence of competition on prices, and lobbying and other forms of promotion to gain commercial advantage have become commonplace. Yet, some have argued that healthcare is special and should not be subject to the impact of market forces. It is thought that access to healthcare needs should be a matter of justice, fairness and equitable distribution alone and that governments should make greater efforts to intervene and take control. At the same time, it has been suggested that patients should have a greater say in their treatment options, and as advocated by a former UK Minister of Health, Alan Milburn, the balance of power shifted decisively away from medical practitioners in favour of the patient.

The extent to which of these approaches is dominant and prevails, rests largely with central government, healthcare professions and the exercise of, or indeed failure to control the exercise of "biopower". Yet, "biopower" is inextricably linked both nationally and globally with capitalist sovereignty. The relevant tectonic power boundaries operate at a variety of interfaces between central government, the pharmaceutical companies, physicians and patients but even governments are limited in their discretion to set and control boundaries. The term "biopower" although not first employed by Foucault, was used by him in the context of the governance and regulation of individuals, populations and society. This is reflected in the continuously shifting strategies and constellations of power. A very simple model would be to envisage government, healthcare professionals, the pharmaceutical industry and patients each positioned at the corners of a square or rectangle denoting sequential, diagonal, dynamic but by no means equal power relationships.

Western and many other governments exercise "biopower" over the distribution and availability of pharmaceutical medicines by a regulatory approval process that evaluates efficacy, safety and quality, and a cost-related process focussed on therapeutic effectiveness and value for money. As such, "biopower" can be seen as a system of prudent "gatekeeping" in which: `The ultimate aim of health care public policy is good care at good prices` (Hall & Schneider, 2009). For its part, the pharmaceutical industry seeks to maximise

profitability by working to enhance sales of its products through innovative R & D, by lobbying influential decision-makers, vigorous marketing promotion and by what is known as “medicalization”, not only to create susceptible bio-molecular targets, but to generate potential markets.

The paper will examine some of the key issues such as tectonic power boundaries, and biomedical citizenship. In particular, it will address the question of whether in attempting to subvert or circumvent restrictions of legitimate governmental “biopower”, Big Pharma is behaving unethically, or rather, shrewdly bypassing counterproductive constraints, and enhancing “biovalue” to the advantage of individual biomedical citizens.

Political Hunger Strikes and Force-Feeding: An Alternative View

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This presentation offers a criticism of the Declaration of Malta on Hunger Strike by arguing that the Declaration’s position against forced feeding is inconsistent with basic medical values, that it is internally incoherent, and that it fails to differentiate among diverse kinds and contexts of hunger strikes.

The two key conceptual errors in the received literature and law on hunger strikers is the claim that hunger striking is "non-violent" and that the strikers are "patients", whose autonomy ought to be respected.

Group hunger strikes by imprisoned political activists is a phenomenon of the twentieth century that has shifted from self-violent and often limited protest of free people against perceived injustice by one's fellows, into an event of radical mutual dehumanization in which hunger striking is the only violent and effective action possible in a struggle that fails recognition in terms of war or other concepts in international law.

An alternative and historical-sensitive conceptual approach to hunger striking is explicated. This approach differentiates "human rights" strikers from "political" ones, arguing in favor of force-feeding the latter but not the former. The alternative approach is derived from international humanitarian law and a philosophy of human rights.

It is then argued that doctors who are committed to political neutrality in the care of the needy should force feed political hunger strikers regardless whether the authorities wish them to survive (e.g. the USA in relation to Guantanamo Bay hunger strikers) or would rather let them die (e.g. The UK in relation to the 1981 Irish hunger strikers).

Healthcare, the Theory of Insurance, and Human Need

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Much of the debate surrounding access to and financing of healthcare is based in competing economic theories of insurance. Conventional economic approaches to the debate in recent essays have asserted the importance of "moral hazard," where it is alleged that incremental additions to healthcare purchases for those who become insured are inefficient, effectively reducing the price of the additional care to zero while creating additional costs. The alleged inefficiency is created whenever the cost of providing the care exceeds the price of the care as measured by the cost of the insurance. On this view, the moral hazard of health insurance decreases overall welfare. Some of the defenders of this view have acknowledged that it ignores the difference between purchases for elective or discretionary healthcare such as cosmetic surgery and purchases for life-saving treatment, such as emergency treatment of serious infections. The social welfare implications of life-saving purchases are very different from the implications of purchases to improve one's appearance. Despite this type of problem with conventional theory, which has been recognized for many decades, the approach continues to drive critiques of increased access to healthcare.

In contrast to the economists' debates, bioethicists have tended to approach the issues of access to healthcare and health insurance from concerns of equality and justice. Here the arguments are less about efficiency than about creating equal, equitable, or perhaps just conditions of access to and financing of healthcare.

In this presentation, I will look at some of these competing theories of insurance as applied to healthcare and defend a different approach, one based on Amartya Sen's work on development, which analyzes social welfare and individual well-being on the basis of *capabilities*, both potential and actual. Central to Sen's approach and its development by J.P. Ruger with regard to access to healthcare is an explicitly normative concept of human flourishing. I will apply Sen and Ruger's work to the healthcare debates, with welfare loss or gain tied to species-typical, "course-of-life" (to use David Braybrooke's term) functional needs, and to the ability to manage risk. Insurance, on this view, is less concerned with "actuarial fairness" and efficiency than with risk-pooling that mitigates risk to those "freedoms" that, as Sen put it, "advance the general capability of a person." In the healthcare debate, chief among the five freedoms advanced by Sen is that of "protective security." Linking protective security to human flourishing, the theory of health insurance is grounded in shared human need.

The connection between narrative competence and clinical competence

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The Medical Education literature considers Narrative Competence as conductive to good communication skills, and to good judgment by means of Narrative Ethics' reflection and reasoning. However, it has not defined clearly what kind of competence this is, and how it may be evaluated.

This presentation highlights the similarities between the *Script Theory* which originates in cognitive psychology and the *Narrative Medicine* approach to clinical care. Because of these similarities, and because of the narrative nature of medical knowledge, it is reasonable to believe that "scripted" knowledge is conductive to the construction of Narrative Competence as a clinical skill.

These theoretical insights are examined by an empirical research in which young physicians take the *Script Concordance Test* (with an experimental version of an *Ethical Script Concordance Test*) and an established psycholinguistic test, the *Story Reconstruction Task.*

“These Other Victorians”: The Premature Birth of a Biopolitical Critique in Baltimore

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Biopolitical critique is reputedly European in origin, due to the central role of Michel Foucault in identifying ‘power over life itself’ as important to the construction of modern society. The proposed paper tracks a current of cosmopolitan, internationalist political thinking (and, to a lesser extent, organizing) among US public intellectuals, tracing their arguments which combined 1920s anthropology with turn-of-the-century sexology, to first analyse and then resist aspects of the moral campaigns and regulation nascent in the Prohibition Era. If hindsight makes it seem as if those ‘Bolshevictorians’ in Baltimore and New York propounded what Foucault famously called the ‘repressive hypothesis’, this paper suggests that writers like V.F. Calverton and Huntingdon Cairns were in fact developing a critical and often campaigning response to the moralistic political times (‘the return to normalcy’) through which they lived.

Calverton (George Goetz, 1900-1940) was an aspiring polymath and ‘radical impresario’ who played a significant role in the US ‘culture wars’ of the inter-war years. His work as a freelance editor for multiple New York City publishers and his being recognized as an early ‘sociological’ (i.e. Marxisant) literary critic overshadowed his

arguably more influential contribution to popularizing anthropology. Compiling the widely circulated anthology *The Making of Man*, the editor positioned the preceding half-century of scholarship under the umbrella of his own master theory of 'cultural compulsives'. The one exception to this pattern was a chapter on law and anthropology (1931: 331-362), presented as a previously neglected specialism, only now summarized effectively in an essay by Cairns, Calverton's attorney.

On the eve of the Great Depression, it appears that biopolitics barely existed as a theory: instead, the intellectual milieu inhabited by Calverton and Cairns searched for economic critiques that would lead to radical social change. When the human body was subject to scrutiny, it was typically as part of the rhetoric of a burgeoning eugenics movement (Currell and Cogdell, 2006), largely repellent to Calverton and his milieu. Faced with eugenic campaigns, intellectuals sought a humanist reworking of 'the science' on race and eugenics.

Cairns's model of legal anthropology situates property rights (ownership) in certain physical practices, such as the Baffin Bay native licking an object to ratify its acquisition. This mode of explanation expresses the earlier impetus of relativizing bourgeois institutions like marriage to suggest the possibility of transcending them, which meant Calverton's intellectual milieu was nicknamed the 'Sex Boys', notorious in the 1920s for popularizing the ideals of free love, predicated upon with several high-profile monographs and

anthologies on this theme. (Tactically, the turn to anthropology was also useful to Calverton, Max Eastman, Edmund Wilson and others for overcoming their reputation as 'Sex Boys'.)

Such political thinking and campaigning also represents a presentiment of the centrality accorded to the body in subsequent accounts of human subjectivity. In tandem, Calverton's anthropological emphasis on 'cultural compulsives' presented people as trapped in an iron cage of ideology and social ritual. Such theories, at odds with his political activity which aimed to change the world, could be treated in this research project as an early C20th attempt to unify anthropology, consciousness and the body into a single theory to be shared with a broad, middlebrow readership. After Foucault (1978), the importance of the body as an analytical category applied to political and social relations increased hugely; my proposed project would consider how this approach was already taking shape in a transatlantic, Anglophone context. The paper will track how these ideals came to articulate a libertarian position bore within it traces of a prototype form of biopolitics.

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Bioethical problems related to transplantation – various perspectives

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Transplantation is a treatment of choice in patients with end-stage renal failure, however there is shortage of donors, what opens door for "kidney black market". Majority of organs used for transplantation are obtained from deceased patients, what does not solve problem of shortage of such organs. New options, such as obtaining organs from living related or unrelated donors, or introduction of controlled compensation for donors of the organs, are proposed and applied in various countries. New policies create ethical problems which must be solved, taking into account cultural specificity of each society.
We studied approach of Polish and American medical students in Poznan University of Medical Sciences to ethical problems related to transplantation. In the first part of the study we compared opinions of

the Polish students from the first year of school (100 responders) and from the last year of the study (99 responders). In a group of students for whom religion was very important approval of the therapeutic use of transplantation was lower (50%) than among their colleagues for whom religion was less important (88%). However in a group of students from whom religion was important support for transplantation was increasing with time and at the end of the study 97% of students supported therapeutic use of transplantation. Majority (90%) of the last year students supported acquisition of organs from the living donors.

In the second study we compared opinions about transplantation of Polish (87 responders; 85% Catholics) and American (86 responders; 61% Catholics) students. In both groups majority of students declared importance of religion in their life (67% and 63%, respectively). Polish students declared higher acceptance for *post mortem* and *ex vivo* recruiting of organs: 74 positive responses vs. 48 among Americans, $p<0.001$. Polish students showed also higher acceptance for various forms of incentives for organ donors, such as tax allowances for living donor (28 positive responses vs.12 among Americans, $p<0.01$), privileged access to specialist health benefits (54 positive responses vs. 19 among Americans, $p<0001$). On the other hand Americans more often than Poles were against any incentives for living donors (33 vs.12, $p<0.001$).

We also asked for opinion about transplantation 74 patients (mean age 64.1±15.8 years; 24 females and 50 males) with end-stage renal failure and treated with hemodialysis. Older patients stronger accepted therapeutic use of transplantation ($r = 0.25$; $p<0.05$) and were less afraid of potential complications related to transplantation ($r = -0.53$; $p<0.0001$). However only 15 patients considered possibility of receiving renal transplant from living member of their family. Expectation of receiving organ from living donor, member of their family was less frequent among older patients ($r = -0.27$; $p<0.05$).
We conclude that Polish students are accepting new approaches in therapeutic use of transplantation. However more work is required in teaching and support of patients who are potential candidates for transplantation.

Reproductive Autonomy as Biopolitical Strategy: A Bioethical Critique of the Liberal Discourse on Reproductive Medicine

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The relation between bioethics and biopolitics is both, a complex and moot issue. While bioethics, on the one hand, is said to uncritically serve predominant political power structures, bioethics, on the other hand, is blamed for wielding power itself, for example, by subtly

directing the public's attention on certain issues and distracting it from others (Gehring 2006). In my talk I want to take a closer look at the relation between bioethics and biopolitics in the field of reproductive medicine. To this end, I will focus on the concept of "reproductive autonomy" which is most prominently used by liberal theorists. Its normative impact, however, reaches far beyond the liberal discourse. Despite several objections to liberal readings of reproductive autonomy, its influence seems unbroken in recent debates on modern reproductive medicine. My thesis is that the appeal of reproductive autonomy results from its simplifying equation with a particular (liberal) mode of political regulation; in this way, it helps to mantle the complexity of ethical issues that reproductive medicine raises.

Present objections to reproductive autonomy concern, amongst others, its identification with "freedom of choice" (O'Neill 2002; Murray 2002) as well as its manipulative underpinnings, for example in the context of prenatal testing (Zeiler 2004). While these are mostly arguments pointing to undesirable political or ethical consequences of reproductive autonomy, my talk, in contrast, will point out an immanent critique of this notion. In particular, by taking the liberal understanding of reproductive autonomy seriously, I will outline its challenges at conceptual and practical level but also with regard to its theoretical justification. To this end, I take a closer look at three applications of reproductive autonomy. With regard to Buchanan's et al. employment of reproductive autonomy (2000) I will argue that

their approach is likely to result in a "genetic arms race" (Sandel 2007) as their argument, contrary to their own claim, fails in setting any limits to parental reproductive decisions, which may thus also embrace decisions for enhancement. Secondly, I draw on a real-life case of conflicting individual reproductive interests in order to show that undifferentiated appeals to reproductive autonomy end up in aporia. Finally, I take a critically look at John Robertson's most prominent and influential work on reproductive autonomy (Robertson 1994). In my analysis, I will show that his approach is based on an implicit value-laden theory of reproductive experiences that contradicts not only his own pretension, but also the liberal notion of impartial justification in general. In the remainder of my talk, I will argue that the practical and conceptual shortcomings of the liberal reading of reproductive autonomy can be overcome by a differentiated bioethical analysis that takes the supra-individual complexities of modern reproductive medicine more thoroughly into account.

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Rethinking Social Justice in Political and Medical Settings of Multiculturalism:
The Israeli Organ Donation as a Case in Point

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One of the most striking features in the Israeli Organ Donation Law, which also happens to be a global precedent in the allocation of organs at the national level, is the system of prioritization that is employed for performing transplants. The law, based on an "opt-in" scheme (i.e. explicit informed consent) includes a clause that gives a higher priority in the waiting list for vital organ distribution to people who either had already signed in the past a donor card, or who are

first-degree relatives of another signee. Hence, faced with the special Israeli circumstances of substantially lower consent rate for organ donation (45%), and significantly lower proportion of adult with donor cards (10%), this law's advocates were looking for a way to increase the willingness of Israelis to donate their organs in case of a brain death. Reducing the 'free-rider' syndrome, then, was a key reason for introducing this precedential prioritization system. Supposedly, therefore, such reason complies with social justice, constituting a primary value in the fields of medical ethics and bioethics, which emphasizes the idea of striving for an equal share of burdens and benefit. The proposed study explores, analytically and ethically, to what extent does the aforementioned law comply with the full essence of "social justice" as it is understood from both medical ethics and bioethics perspectives. Particularly, the study focuses on the multicultural facets of contemporary Israeli society and politics as well as their relevance to our understanding and application a social justice in general, and within the context of the organ donation law, specifically. Based, on these explorations, the study suggests that the system of prioritization in the Israeli organ donation law cannot be justified ethically. Instead, an alternative scheme is sketched, which is a blend of an "opt-out" system (i.e. presumed consent) together with an enhanced sensitivity and accommodation towards the beliefs of individuals from religious minority groups.

Molecular Epidemiology and clinical features of hepatitis C virus (HCV) in the Sindh,

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*Background***:** Highly variable genome of HCV in different geographical regions of world has made imperative to conduct local population studies. HCV affects more than 200 million people worldwide and is a leading cause of liver diseases such as hepatocellular carcinoma. Various reports on HCV prevalence have been published from different regions of Pakistan, but there is almost no data available from interior Sindh of Pakistan and now rural area of Sindh, Gambat District khaipur has become a serious health issue. This comprehensive study was carried out to estimate the increased frequency of hepatitis C virus infection and its related risk factors in rural area.

Methods: A total of 212 blood samples were collected from Gambat Institute of Medical Science College (GIMS), Sindh, Pakistan from year 2010 to 2012. Detailed patient's history was asked to complete a questionnaire of clinical and epidemiological data for each patient. All patients were tested for anti-HCV antibodies by ICT, ELISA, PCR and genotype. Results were compared with various risk factors.

*Result***s:** Cases were significantly more likely to have received use of injection (42%) and reused of injection (17%) in this study. Sindhi's were more predominantly infected with HCV than other ethnic groups of Pakistan. The prevalence of anti-HCV antibodies was significantly higher in males (53.77%) than in females (46.23 %). HCV infected men in their early age group while female acquired more infections in their middle age group. Genotype 3a is most common in HCV infected patients.

Conclusions: This study showed a high prevalence of HCV and established a high carrier state of clinically silent HCV infection in Gambat City Sindh, Pakistan. It was observed that therapeutic injection, needle stuck and medical procedure were factors most strongly associated with HCV infection.

Keywords: Hepatitis C virus (HCV); Genotype; Immunochromatographic Tests (ICT); intravenous (IV); Hepatitis B virus (HBV)

Approximations to Wittgenstein's Therapy of Philosophy and Therapeutic Philosophy in Regards of Some Bioethical Issues

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Wittgenstein's philosophy – early and late – is regarded by the majority of the scholars (and was conceived by Wittgenstein himself as well) long since as one bearing and demonstrating a strong therapeutic character. In one sense it can be understood as a philosophy providing insights as a means to achieve a sort of therapy of the philosophy, or at least of certain philosophical traditions and age-old philosophical problems. In another, Wittgenstein's ideas and conceptual framework can also be interpreted as approaches that can supply us with – via his grammatical investigations and objects of comparisons – tools to practice a form of genuine therapy for our everyday life-problems. Carl Elliott, in his scholarly monograph, *A Philosophical Disease,* goes a step further, and presents that Wittgenstein's trail of thoughts – through reading it from a bioethical perspective and applying his method and concepts to particular biomedical problem-fields – can be comprehended as remarks bearing relevance on the field of the philosophy of (medical and psychological) therapy as well. My paper aims, on the one hand, to recapitulate briefly and to criticize in some regards Elliott's understanding of Wittgenstein in general, and more particularly his

peculiar comprehension of Wittgenstein's philosophy as a philosophy of therapy. On the other hand, also in the spirit of – Elliott's and others' – *applied-Wittgensteinian* approach, I will focus on the re-reading and thematization of certain pivotal concepts of Wittgenstein – such as the ineffability of ethics, his comprehension of and 'cure' for antifoundationalism and antiessentialism, and his relativistic remarks – related to bioethical and biopolitical issues, with special regard to irreconcilable (looking) conflicts in the field of medicine and biopolitics.

Biobanks: which ethical framework in public health genomics?

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Public health is the societal approach to protecting and promoting health and improving the well-being of communities, usually through social actions. The collection and storage of human tissues, cells and products (DNA, proteins, etc.) for different purposes as research, criminal investigation, human identification can be defined as biobanking.

Public health genomics represents the responsible and effective translation of genome-based knowledge and technologies for the benefit of population health. It is becoming increasingly global and

collaborative, aided mainly by wide bioinformatics applications and resulting from the need for larger and more diverse datasets to study the significance of genetic variation within groups. This will involve the networking of larger databases of samples and data around the globe.

At the same time, there is an increased need for new solutions in order to translate in health planning programs the results of genomics research findings, for the benefit of the general population. The results of these studies could be of paramount importance for planning effective and qualified interventions for public health priorities, for designing national health strategy and developing preventive medicine interventions.

A viable and equitable process of connecting genomics research to public health interventions requires well-established and peculiar ethical standards and research policies.

Genomic research performed through biobanks should meet the highest ethical, legal and socially appropriate standards. Similarly, genomic biobank research should also be accompanied by structured policies to guarantee that research findings and results are useful for the greatest public health needs, and that human rights, as well as research ethical standards are respected.

Public health, differently to clinical medicine, is concerned more with populations than with individuals, and more with prevention than with cure, so the principles of medical ethics could not be simply and

automatically applicable to public health. The fundamental aspect of public health ethics is balancing the need to exercise power to ensure the health of the general population and to avoid abuses of such power.

In addition to standard ethical issues associated with biomedical research more generally, public health genomics research poses special challenges in different important areas, as anonymization of samples and data, information and consent to the donors, and the return of research results to the donors.

Furthermore public health genomics, should aim to improve the general knowledge of genomics among communities and develop tools to enhance the understanding, use and acceptance of genomics research by the population, building public trust and confidence in this kind of research.

Human rights and biomedical research in Africa: Towards an effective regional regulatory framework to protect the rights of vulnerable populations

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Numerous scientific reports and international case law have highlighted failures by researchers and research sponsors from

developed countries to adhere to international ethical codes when conducting biomedical research in Africa and other developing countries. Recent evidence indicates that even in African countries where national ethical guidelines are present, the human rights of research participants may still be violated. This is exemplified by international clinical trials on vaginal microbicides, where cumulative evidence has indicated that first-generation microbicides such as Nonoxynol-9, Cellulose Sulphate, and C31G (SAVVY), increased the incidence of HIV infection and other physical injuries amongst trial participants. Despite these adverse outcomes, the human subjects of such research activities are never compensated for their injuries. This is probably based on the defense that participants signed consent documents, or because they live in a region where diseases such as HIV-AIDS are endemic or life expectancy is low, or perhaps due to the fact law enforcement is lax in most African countries, rendering local populations vulnerable to exploitation by unethical researchers and sponsors.

However, it is established practice in European and other developed countries that human subjects who are inadvertently injured during clinical trials are readily compensated either through ex-gratia payments by the pharmaceutical industry or through court mediated tort action or other compensatory mechanisms. Why are similar human rights provisions not applicable during clinical trials Africa? This reinforces accusations of double standards, and reinforces the

need for an African regional regulatory framework to guide the conduct of biomedical research and enhance protection for vulnerable African populations. Such regulations may include a no-fault compensation scheme, or compulsory insurance for researchers and sponsors, to help remedy some of the foreseeable harm that occurs during human biomedical research. It would therefore be prudent public policy for African countries through the mechanism of the African Union (AU), to develop and implement directives to guide the conduct of human biomedical research in Africa, similar to European Union (EU) directives which regulate the conduct of biomedical research in European countries. A unified approach by African countries will provide assurance to the international scientific community, that research conducted amongst African communities is based on the same ethical and legal standards available to research participants in developed countries. Such regulations would also promote more ethical research practices in Africa, enhance human rights, and would go a long way towards unifying and simplifying the fragmented national laws and regulations currently in existence, which are derived from the different legal systems of previous colonial regimes in Africa. This proposed regional regulatory framework may contribute towards enhancing the ethical conduct of biomedical research in African countries.

Keywords: Research- Ethics- Regulation-Compensation-Justice-Human Rights-Africa

The ethical problems healthcare workers face in disaster settings

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The classical definition of the term “disaster” is the situations where the needs exceed the resources available. In disaster settings, healthcare providers work in conditions different than their daily routine. The dramatic environment which demands urgent and vital actions might pose different kinds of value problems, such as making life&death decisions by triaging the patients, determining the limits of duty to care, coping with the problems related to reliefs, or carrying out researches in the affected population. These special circumstances augment the unequal nature of the relationship between the caregiver who has the specific resources and the patient who needs those resources more than ever. In addition to the ethical problems emerged in the relationships with patients, healthcare workers might have tensions in the relationships with relief organizations, unprepared volunteers, the media, and especially with official authorities. Disaster situations inevitably create gaps in the hegemonic area of the power of authorities, which is needed to restore by showing the owner of the power immediately, decisively, and sometimes harshly. Health is one of the major topic to intervene, and healthcare is one the most important tool in that sense. But healthcare workers, as moral agents, have their own professional values, which urge them not to cooperate

with the demands conflicting to the patients' best interest. What do they do in such situations? What are the types and nature of the ethical problems specific to disaster settings? How should they create a justifiable option for action while respecting professional values and right to health? In order to contribute to the moral deliberations about those questions, we have planned to carry out a qualitative study among healthcare workers. In-depth interviews are being carried out in various cities of Turkey with the participation of healthcare workers who had experience in various disasters including Marmara earthquake (1999) and Gezi protests (2013). In this presentation, the results of this study will be presented. Considering the fact that the universal codes of ethics usually fail to guide them appropriately and medical education usually does not include topics specific to disasters, it is hoped that the study would contribute to the efforts for developing ethics guidelines, which could help healthcare workers to make justifiable decisions while they organize and provide services in disasters.

Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities.

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Making decisions is an important component of everyday living, and issues surrounding autonomy and self-determination are crucial for persons with intellectual disabilities. Adults with intellectual disabilities are characterized by the limitations in their intellectual functioning and in their adaptive behavior, which compromises three skill types (conceptual skills, social skills and practical skills). Though persons with intellectual disabilities are characterized by having these limitations, they are thought to face significant decision-making challenge due to their disability. Moving away from this generalization, Article 12 (equal recognition before the law) of the UN Convention on the Rights of Persons with Disabilities addresses this issue od decision-making for persons with disabilities, recognizing the right to legal capacity. The Convention does not provide a definition for legal capacity but as one scholar phrases it as "legal capacity…Provides the legal shell through which to advance personhood in the life – world. Primarily, it enables persons to sculpt their own legal universe – a web of mutual rights and obligations voluntarily entered into with others…Legal capacity opens up zones

of personal freedom" (Quinn, 2009). Essentially, legal capacity means recognizing the right to make decisions for oneself even for those with higher challenges in decision-making. The legal response in many jurisdictions has been and continues to permit a third party to make decisions on behalf of the persons with the intellectual disability, known as substituted decision-making. Article 12 is moving away from substituted decision-making and in the direction of supported decision-making to support persons with intellectual disabilities to exercise their legal capacity. Supported decision-making is a process by which a third (e.g. support person) assists or helps a person with the intellectual disability to make legally enforceable decisions by themselves. The objective of this paper is to show the conceptual connection between supported decision-making and the preservation of personal autonomy for persons with intellectual disabilities. The specific aims are, (a) to provide a description of Article 12 relating to legal capacity and its interpretation (substituted vs supported), (b) to explain what supported decision-making is based on normative description, specifically looking at Bach and Kerzner`s model of supported decision-making, (c) to define autonomy using John Stuart Mill`s concept of autonomy, and (d) to argue why supported decision-making is conceptually connected to personal autonomy by applying Mill`s concept of autonomy to the situation of persons with intellectual disabilities. This is done through a conceptual analysis of supported decision-making specifically looking at all documentation

to do with supported decision-making specifically by Michael Bach and Lana Kerzner (2010) and various academic articles on supported decision-making.

The biopolitics of molecular epigenetics: Liberal individualism through molecularization and biomedicalization

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In the past decade, molecular epigenetics – a novel field exploring the molecular interplay between living conditions, gene expression and health – is garnering attention and interest from both the biomedical and the social sciences communities. Two dominant interpretations of these findings have emerged. First, a biomedical translation provides an additional argument in favor of understanding diseases – and their associated potential treatments – at the molecular level. This approach opens new horizons for the development of novel technologies that would detect new health risks *embedded* within the bodies of patients through epigenetic processes. Thus, the study of the 'epigenome' and the 'histone code' could arguably be useful for the development of novel strategies of personalized medicine (e.g. pharmaco*epi*genomics). Second, a social translation introduces new arguments in favor of addressing social health inequalities. These

arguments complement existing epidemiological ones, but are based on the molecular level. They justify public health strategies that address disparities in the distribution of social determinants of health (e.g. socioeconomic status).

In this paper, we argue that contemporary biopolitical and bio-economic contexts are particularly favorable to the biomedical translation of knowledge in molecular epigenetics. We present two important *trends* in Science and Society – molecularization and biomedicalization – that are likely to favor a biomedical implementation of epigenetic knowledge at the expense of a more social implementation. We argue that these trends are closely related to the increasingly prevalent current of liberal individualism in Western societies. This paper is thus a call for precaution against an overly simplistic biomedical translation of epigenetics and conceptualization of health inequities. It cautions against an over-emphasized focus on *internal* determinants of health (e.g. DNA methylation) rather than *external* determinants of health (e.g. social adversity). Such a misguided emphasis would fail to recognize the urgent requirements for public policy interventions to reduce health inequalities by addressing socio-economic and environmental disparities.

Chronic Disorders of Consciousness and *Homo Sacer*

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While much significant research is being done on the problems that patients may have in making sense of – interpreting – their lives in the face of chronic illnesses, chronic disorders of consciousness (CDoC), such as persistent/permanent vegetative state and minimally conscious state, pose a related, but distinct, problem. The patient typically is at best only intermittently aware of their condition, so the burden of interpretation falls primarily upon relatives and carers. Relatives and informal carers face a fundamental difficulty in knowing how to go on in a meaningful social relationship with a patient who is alive and yet unaware. The patient with CDoC appears to defy the everyday categories through which we strive to make sense of other selves as persons, acting intentionally and meaningfully, and of our relationship to them.

By drawing on Giorgio Agamben's *Homo Sacer*, this presentation will exploring the potential that the conception of 'homo sacer' (as one who can be killed but not sacrificed) might have for articulating the ambiguities of relatives' experiences. Taking a cue from his analysis of the social tie – that 'originally has the form of an untying or exception in which what is captured is at the same time excluded' (*Homo Sacer*, part two, section 4), and drawing on Agamben's

discussions of the sovereign body and the sacred body (part 2, §5) and of brain death (part 3, §6) – the presentation will argue that the body of the patient with CDoC undergoes complex and competing interpretations from relatives and physicians, precisely insofar as the social tie that the relative may strive to sustain, in an attempt to go on, coherently, in their relationship with the patient, also abandons the patient to the threat of death, reducing them to bare life. Unpicking Agamben's analysis may allow for a better understanding of the relatives' relationship to the patient, and an acknowledgement of the point at which, in a strange inversion of Agamben's example of a king who dies in effigy after the death of their body (part 2 §5), the patient may be allowed to die before their body dies.

Facing Animals

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This paper explores animal model practices using the phenomenological notions of the ‘face’ and ‘animality’. Based on an ethnographic study of osteoporosis research using rat models I argue that relating animal model results to humans relies not only on rational grounds to anthropomorphise those rats but also on the felt experience of the rats as animals with faces. Whether or not we want to “know”

animals by looking at their faces, the possibility of so doing is implicated in our quest for knowledge through animal models. Specifically it makes our responsibilities to them as others with faces hard to escape.

Following Merleau-Ponty David Morris (2007) proposes that 'animal faces' are of special significance in the world as experienced by us, using our onto-logic as animals. Reading faces lets us recognize how we-each-other 'are', opening up a realm of invisible, mental or emotional 'being' to the realm of the visible, physical being. Faces are visible surfaces communicating what is internal or invisible. They are special surfaces that can manifest something inferred from the realm of the invisible. Morris juxtaposes looking at faces with looking at the internal workings or organs: even if we imagined ourselves having transparent skins, making all our internal processes seen, we would still need to look in each-others' faces to say how we 'are'.

I argue that knowing through animal research is inextricably tied up with the possibility of knowing animals through their 'face': understood as the surfaces facing us - faces and bodies. Experimental design in animal studies negotiates between conceiving of the animals as "faceless" expendable, laboratory material: bought, quality checked and discarded once used, and as animals we face, whose behaviours, pains and bodies we relate to ours. Even if experiments focus on aspects of an animal other than its face, animal experimentation

involves encounters with the animals as others with faces and knowing the animals through their faces.

I examine how researchers negotiate the dual role of the animal as faceless and as an other with a face. Specifically I focus on the sacrifice stage of an osteoporosis study using ovariectomised rat models. During sacrifices the living animals waiting to be sacrificed are kept at a distance from the animal being sacrificed to prevent them from smelling the blood on the surgical table and becoming agitated. Manifestly it is the other animals that are to be protected through this decision. However it arguably keeping the living animals at a distance prevents human researchers from facing those animals. My results show that researchers get on with work more easily once they focus on their specific tasks, while emotions are harder to control when looking at the animals waiting to be sacrificed. Keeping living animals apart from animals under operation also means keeping humans from facing these other animals.

Animal experimentation aims to get at humanly relevant answers. However the categorical and felt alignment between rats and humans as animals with faces will by default raise ethical questions.

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Designing "personalized" RCTs: the case of BiDil

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There have been a number of philosophical critiques of the method for scientific testing called a “Randomized Clinical or Controlled Trial” (RCT). For instance, Cartwright (2007) disagrees with ranking RCTs at the top of evidence hierarchies evidence argues that clinical trials should not trump other methods of causal inference when looking to establish the efficacy of a treatment, Worrall (2003) criticizes the epistemic cache of randomization and Howick (2007) questions the feasibility and importance of double blinding. This paper gives an example of an RCT that did in fact backfire but on epistemic grounds much more basic than these. This RCT was deemed epistemically dubious on a much more mundane matter: the selection of its target.

This is the case of the African American Heart Failure Trial or A-HeFT [I-III]. A-HeFT was a randomized, double-blinded placebo-controlled clinical trial that tested a heart disease drug called BiDil on 1,050 people self-identified as African American. A-HeFT was terminated early because the treatment was so efficacious it was deemed unethical to keep withholding it from people on the placebo arm. Passing the trial led the FDA to grant its approval to BiDil (in June 2005) for its target, which made it the first drug to come out with a race-specific label on.

So what was controversial about BiDil? A-HeFT demonstrated its efficacy on its target and emphatically so. What seems to have troubled researchers here was the selection of this target population as a target population to begin with. There was a great controversy in the science studies researchers studying the case (cf. Kahn 2004, Sankar, Kahn and Sankar, Ellison and Kahn, Ellison). And the epistemological critique launched against BiDil can be (very roughly) summed up as follows: BiDil didn't show that it didn't work for non-African-Americans. It did not demonstrate its inefficiency in the complement of its target.

Whether or not this critique is correct the case brings up an interesting problem. What warrants the selection of an RCT's target as a target? As Max Weber might ask: how do we select the objects of our (RCT) study? In the case of A-HeFT both biological and social scientific understandings of race and ethnicity were factored into the debate and may explain why this, in the context of recent American race history, was flagged as a dubious selection to make. But such assumptions may lay hidden in other cases.

Biomedicalization and the social construction of aging: theoretical and ethical problems

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Critical social gerontologists such as John Vincent critique efforts by the natural sciences to develop new interventions into aging with the concepts of biomedicalization and the social construction of aging. Vincent derives both concepts from the tradition of Foucault and the school of Frankfurt, however without methodological clarity. His accusation is that the biological concept of aging is a result of an implicit ageism of biogerontology, and part of a social construction of the aging process with the goal to submit it to biomedical control and related commercial interests.

However, there is a lack of methodological clarity in Vincent's criticism. It remains unclear how his concept of a social construction of aging has to be interpreted. This may lead to the undesirable consequences of a theoretical position, which may be called a sociological idealism and an ethical relativism. While the ethical foundations of his own suggestion for an accomplished life remain unjustified, the experience of illness and frailty by older people becomes simply inauthentic from this perspective. Both problems point to basic difficulties of comparable approaches. The big challenge is how such approaches can be integrated with knowledge

deriving from the natural sciences, and with ethical theory. A possible way will be briefly sketched based on John Searle's theory.

The Biopolitics of Bioethics: Love Drugs and the Morality of the Neuro-molecular Gaze

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In a series of recent publication Savulescu *et al* (e.g. 2008, have analyzed the ethics of 'love drugs,' a neuro-technological innovation they appear to consider a near future possibility. These articles, and the wider dissemination if their arguments, - not least by the authors - demonstrate that neurobiological discourses now compliment those of the psy-sciences in the reflexive process in which human beings construct *human being*. As with other discourses, the knowledge of the human sciences is disseminated by bioethical debates. The case of love drugs offers a particularly instructive example of this propagation, as it makes clear that bioethical discourses not only construct *human being* but also construct the *ethical human being*. In regards the first notion, the analysis of love drugs presents an account of intimate life consistent with Giddens' conception of the 'pure relationship' (1993) and therefore subject to the same critiques that have been leveled against it and its role in modern life (e.g. Jamieson

1999). In regards the second point the accounts presented implicitly suggest that the 'pure relationship' is a morally neutral relation which can therefore be properly understood in ethically thin terms. Basing their view on the principle of 'marital autonomy' they analysis they offer suggests that neurochemical technologies, such as drugs for love, are themselves morally neural phenomena.

However, as Verbeek suggests "[w]e are as autonomous with regard to technology as we are with regard to language, oxygen, or gravity" (2011:155) or, we might say, as we are with regard to our spouses. Whilst a drug for love - or, indeed, the idea and bioethical analysis of a drug for love - can be considered as promoting the autonomy of both the individual and the (pure) relationship it can also be considered as a morally conservative phenomena. Whilst bioethics often considers itself to be at the cutting edge, radically questioning our moral norms, these papers demonstrate a (biologically) normative perspective consistent with contemporary cultural norms that regard loving (sexual) relationships as synonymous with monogamy and marriage. As a consequence these articles promulgate these norms and, through a further deployment of the neuro-molecular gaze (or, perhaps more accurately, imagination), thereby sow the seeds for further 'ethical' uses of love drug technology.

Such a perspective suggests that 'bioethics' itself is, or can be considered, a technology and a human science with 'biopolitical' implications. The analysis presented in these papers, the pure

relationship and the neuro-molecular gaze collectively constitute a perspective that is 'anti-culture.' Through the recognition and reintroduction of human being as an inescapably social phenomenon we can reflect on the moral relevance of our cultural ethos for intimate relationships and the analysis of neuro-technologies that purport to enhance them.

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An Economic Reason for the Failure of the Idea of Synchrony between Physicians: Policy and Ethical Implications

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Suppose a physician believes that medicine as a whole achieves the best results when every practitioner assumes responsibility for each patient under his or her care. In making decisions, the primary focus of the physician is the good for this patient here and now, not the good for a distant patient or the good for society. The idea is that synchrony between physicians, meaning each physician focusing on the good for his or her concrete patients, optimizes everyone's health outcomes. In other words, the physician makes decisions to optimize the good for a particular patient and combined all these decisions by individual physicians for their patients, through some sort of invisible hand mechanism, lead to the greatest good for all. The idea has a certain common sense appeal to it, which probably explains why David Eddy attributes it to many physicians in his book *Clinical Decision Making: From Theory to Practice* (1996). If synchrony between physicians indeed optimizes overall health outcomes, then that seems to plead in favor of a laissez-faire attitude toward managing physicians.

My purpose in this paper is to show there is an economic reason to doubt the idea that synchrony between physicians optimizes health outcomes for everyone. I do so by relying on George Akerlof's

distinction between near-rational behavior and perfectly rational behavior. The idea of synchrony assumes that physicians are perfectly rational actors, taking into account all the information available to them and making sophisticated predictions about the future implications of their actions, whereas in reality physicians are near-rational actors, using only the information necessary to treat a concrete patient in the here and now. The collective result of the decisions of near-rational physicians focusing on the good for each individual patient does not optimize health outcomes for everyone, but instead makes some patients less well-off health-wise than they could have been.

The failure of synchrony to optimize aggregate health outcomes has important policy and ethical implications: First, it strengthens the case for rationing in health care, because the near-rational decisions of physicians need to be corrected in order to optimize health outcomes. Second, it limits physicians' claims to autonomy, because supposedly it is the autonomy every physician has to do the best for each concrete patient combined with synchrony that optimizes overall health outcomes. However, if synchrony between physicians does not optimize health outcomes, then the claim to autonomy loses at least some of its power. Even though both implications point firmly in the direction of managing physician behavior from the top down, and hence in the direction of greater political involvement in optimizing health outcomes, I tentatively suggest that institutional design has the

potential to be an alternative way to optimize health outcomes. Of course, institutional design does not rule out political involvement, but it does require an altogether different political approach.

The contribution of Foucauldian heritage to sustain the subjects of bioethics and biopolitics

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In the lesson *Naissance de la biopolitique* (1979), Michel Foucault set bioethics and biotechnology within the context of biopolitics. From the production of human capital to the present protocolisation of medicals practices, the disclosure and critic analysis of process of normalisation remain necessary, and even more practices to sustain the reconstruction of precarious subjects and responsibility of all actors of care. We will share haw the heirs of Foucault, especially Joan Tronto (ethics of care), Judith Butler (ethics of reciprocal protection), and Guillaume Le Blanc ("social clinic") suggest criteria in order that the whole social actors should play an effective part in medical practices and politics, and bioethics research et social solidarity should be more inclusive.

Epistemology of East-Asian traditional medicine

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Introduction: Integrative medicine is a relatively new field that offers a new, more holistic approach to medicine to satisfy the needs of the public by unifying biomedical conventional medicine and non-conventional medical practices; complementary and alternative medicine (CAM), which are not yet biomedically verified. What we call integrative medicine emerged in the early 1990s, and its potential is promising; however, there is crucial need to increase knowledge in this field.

My project will contribute to understand how it is difficult to evaluate the efficacy of CAM therapeutics. While recent researches emphasize reductionist way, I argue that, in acupuncture study for instance, it is next to impossible to follow the causal relationship with reducing interventions to physical entities.

My talk will compare the history of Chinese traditional medicine (CTM) and Japanese traditional medicine (JTM) so as not to judge which is superior but elucidate their difference. Although current studies tend to take CTM mostly as an object of the research: acupuncture, moxibition and so on, they have not so far been able to succeed in proving the sufficient efficacy of CTM. The central dogma of the CTM is the concept of "*Qi*", which is enormously difficult to be

treated in the framework of modern science. While JTM as an offspring of CTM, JTM is freer from the concept of *qi* because through its history JTM has reduced influences of excessive theorization in CTM. I argue that JTM is preferable to CTM for scientific study.

Questions: This chapter is designed to provide the background that allows me to introduce an argument that I develop throughout the dissertation: that integrative medicine study implies an essential dilemma that prevents researches from progressing, which derives from out-of-balance in-between disregard and respect for CTM's theory such as concept of *qi*, Yin-Yang thought, logic of five elements because of difficulty to handle them in biomedical disciplines. More specifically, I argue that in order to avoid this dilemma it is important not to operate as though *qi* doesn't exist but to draw a line between what they can treat within a framework of modern science and what they cannot.

Arguments: In my talk I want to propose some reflections upon the price that was paid for this disregard for the theory of CTM. I would argue the special character of today's dominant evaluation methodology – randomized controlled trial (RCT) – and the ways in which excessive reliance on RCT distorted the essence of CTM and amplified the dilemma. And also, I want to propose some reflections upon the price that will be paid for the introduction of central dogma of CTM into scientific study. I would suggest that the ways in which

researches might loose in turn scientific certainty, clarity, and objectivity if they make much of the concept of *qi* or human sensory subjective diagnostics system in biomedical study. Finally I would like to note advantages in introducing JTM into scientific study and the ways in which JTM has reduced influence of the excessive theorization in CTM.

Bioethics as a politics of its own. About Van Rensselaer Potter's topicality

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When Van Rensselaer Potter coined the word « bioethics » (*Bioethics: Bridge to the future*, Englewood Cliffs, New-Jersey, 1971), he may have not anticipated how the word would be successful. But the word happened to be understood in quite a different meaning he had given to it. He wanted to express a concern about the survival and well-being of the human population considered as a whole and embedded in its environment. *In Global bioethics: building on Leopold legacy* (East Lansing, Michigan, 1988), he expressed his criticism about « bioethics » such as it developed: mostly at the bedside of the patient. He insisted on the necessity to tackle the issue of human survival and its relationship to environment, from which human beings derives

their resources. Among other things he advocated for a strong reproductive control. He emphasized the necessity for human societies to think of their relationship to the environment for a good and healthy life. He declared that bedside ethical dilemmas were vain issues without this change of paradigm.

Such a critical view on bioethics allows us to tackle the question of how are interwoven bioethics and politics? Van Rensselaer's understanding of bioethics immediately highlights its political dimension: normative choices are to be made for the human population as a whole, and not only for individuals experiencing « tragic » situation for their own health. From this point of view, Van Rensselaer's work is still worth being read and meditated.

Besides, through this understanding of politics, he seems to offer an alternative understanding to biopolitics or biopower, especially in the foucaldian meaning of the words. As a matter of fact, he does not focus on style of governing. He rather addresses the issue of *collective normative choices* that will determinate the future of humankind. He makes of these collective normative choices a democratic issue.

Finally, he attracts our attention to the question of human beings' relationship to environment. The reference to Aldo Leopold seems to imply more than a simplistic view of the environment as a basket of resources available for men, to be used wisely.

Because of this three elements, it is worthwhile to assess Van Rensselaer Potter's topicality on the topic of « bioethics and biopolitics ».

After dedicating some time to present these three aspects of his thought, my presentation will offer a proposal to give a contemporary content to his view of « bioethics », based on my current research about « environmental risks » for human health and the necessity to make some collective normative choices to face them.

Volunteering to "non-therapeutic" research: benefits, risks and "due" inducement

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There are several types of human research that explicitly offer no prospect of direct benefit to study participants. Research involving healthy volunteers, such as Phase I clinical trials or the so-called "human challenge studies" in vaccine development, are perhaps the most clear examples of these studies. Ethical challenges related to this type of human research are mainly related to the level of risks to be justified, defining vulnerable groups and proper incentives to be used to recruit potential research participants. The concepts of "acceptable risks" and "undue inducement" have been used and developed in both

academic and policy making discourses to deal with the mentioned ethical issues. This paper will examine these basic concepts and related normative principles in the context of international research ethics guidelines which are supposed to provide criteria for research ethics committees as well as researchers to evaluate the ethical acceptability of biomedical research projects. It will be argued, however, that these guidelines do not provide a clear and consistent framework for the ethical decision making in case of research without a prospect of direct benefit. The problem becomes even more complex when "non-therapeutic" research involving patients is being considered. An attempt will also be made to analyze how the concepts of "acceptable risk" and "undue inducement" are being framed at the level of international policy making bodies.

ADHD - Social dysfunction as criterion for a medical disorder

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Having a medical disorder can imply different undesired aspects: pain or diminished well-being, reduced life expectancy, and/or some kind of dysfunction of the organism. Dysfunction - according to many approaches crucial in order to define the disease concept - is however a complicated concept, as it requires some goal or plan that should be

achieved, and is not achieved properly. In order to define the normal and the diminished function of an organism independently of the environment, we are notoriously in need of defining a standard surrounding. In the context of medicine, we usually do not do this explicitly, but we take for granted a reasonably adequate temperature, food, water and oxygen supply, absence of toxic or otherwise deadly substances and conditions etc. On this background, we try to find a set of reasons for which an organism does not feel well, has a diminished life expectancy and/or does not function according to its usual capacities.

Obviously, many medical disorders lead to diminished social functioning which is usually excused (e.g. sick leave). It is however worth a deeper discussion if the social dysfunction per se should be seen as symptom of a more concrete diagnosis, instead of focusing more on the problems of the organism itself. In ADHD, in contrast to most other disorders, social dysfunction is an integral part of the diagnosis. ADHD is described by a set of symptoms, some of which are primarily socially defined like “Not being able to wait on their turn”, or “disturbing others”. Moreover, there are general conditions that have to been fulfilled in order to have the condition ADHD: one of them is that there is a clinically relevant reduction of social, academic or occupational functioning. If a person is unable to concentrate and has a clear hyperactivity, but is accepted socially, not expected to achieve academic merits, and has an occupation that s/he

is able to fulfil, so s/he has no ADHD. In our paper, we would like to discuss on how many levels and how redundantly ADHD relies on social interaction, and we would like to present some possible alternative explanation models to the problem, questioning the current borderline between medical and social explanations for diminished functioning because of inattention and hyperactivity.

Different Approaches to Converging Technologies in US and Europe

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In 2001, the first NBIC workshop organized by the National Science *Foundation* was held in US with the aim to explore the possible technological progress made by NBIC technologies. (The acronym NBIC stands for nanotechnology, biotechnology, information technology and cognitive science.) After this workshop a report called Converging Technologies for Improving Human Performance was published, in which they introduced the vision of human enhancement, which could be achieved in many fields of human performance – our sensory, motor skills, cognitive abilities, appearance...The objections of opponents of NBIC project were defended by the main idea or motive of advocates: they claim we need

this technological progress and innovation to realize the human potential and according to this we should be ready for the revolutionary changes.

The NBIC project is not the only one, but probably the most controversial. In 2004, High Level Expert Group (HLEG) published the document Converging Technologies for European Knowledge Society (CTEKS). It is reasonable to consider it as an answer to US's NBIC project. In contrast, the European concept is neither explicitly focused on the human enhancement, nor it takes into account just NBIC technologies as converging technologies, but also the other technologies and knowledge systems mentioned in CTEKS as a *Nano-Bio-Info-Cogno-Socio-Anthro-Philo-Geo-Eco*-Urbo-Orbo-Macro-Micro-Nano.

In this paper I will analyze the differences between these two approaches, NBIC and CTEKS. For example, I will compare their foundations, approaches to converging technologies and to human enhancement, the actual and possible problems related to them.

On the relationship between bioethics and biopolitics

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This paper discusses the conceptual and practical relationship between bioethics and biopolitics. The paper proceeds by identifying certain ideal-types about the nature of bioethics which, it is argued, illustrate two ends of the spectrum upon which discussions of the field of bioethics occupy. They are constructed according to two criteria: the first concerns the scope of bioethics, which includes the aims of bioethics and its problems; the second involves the details of the method(s) of bioethics including the use of empirical data. With respect to the scope of bioethics, two models are discussed which offer a broader and a narrower focus for bioethics. The first suggests that bioethics is, or should be, a global undertaking, with a broader and renewed focus on global justice, basic health needs, and our relation to the environment. The second suggests that bioethics is primarily concerned with a 'northern' agenda, which focuses on the problems with healthcare systems and issues thrown up by advanced biotechnology. With respect to methods, the idea of bioethics as a purely, or primarily, philosophical enterprise is discussed and a more interdisciplinary model is sketched. These versions of bioethics are used as the basis for a comparison with bio-politics.

The paper continues by examining some prominent (although by no means all) characterisations of biopolitics and compares them with the bioethical models. ‘Biopolitics’ is used to refer to many issues that range from bioterrorism and security issues to biotechnological developments and the ethical issues that arise from these, and from the nature of state control and surveillance over its citizens, to a concern with the rise of social philosophies such as neo-liberalism. One possible interpretation of the relationship between bioethics and biopolitics is that they cover much the same ground, but that somehow biopolitics is broader and deeper, focusing on the wider political context of policy and regulation, and that this is not part of the remit of bioethics. However, it is argued in this paper that this has some plausibility only if we adopt an unnecessarily narrow definition of bioethics in the first place. Once we shift our focus in bioethics to appreciate the necessity for broadening our horizons – perhaps to a ‘global bioethics’ - and once we understand the necessity for empirical research from all relevant sciences, we begin to see that bioethics does have a legitimate concern with the type of questions and analyses hitherto associated with the field of biopolitics.

Ethicists herding the sheep for the big bad wolf: European philosophical tradition and applied ethics in the ripe capitalist world

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Here is my story. At the end of it, you will find my plea to the audience. Historically, there were three European moral doctrines: the Aristotelian, the Kantian, and the Utilitarian. At the turn of the twentieth century, they all collapsed, as their presuppositions became intellectually unacceptable. Alternative ways forward during the twentieth century included totalitarianism, existentialism, and post-modernism. The optimistic version of post-modernism held that social constructivism and an emphasis on manageable-sized communities could make life tolerable even in a post-totalitarian capitalist world.

Since there was a need for social rules, many academics turned their attention to social ethics and political theories. The quasi-contractarian, socialist, libertarian, egalitarian, and communitarian solutions, and many others, were (and are) intensively studied. At the same time, an applied turn occurred in ethics. It was thought wise to study practical issues and to apply ethical and political theories to them. Bioethics, business ethics, military ethics, and many other branches of applied ethics were born.

It is, however, difficult to understand why all this happened. The objections against European moral doctrines still hold, and similar objections can be launched against the political theories, as well. They are, after all, offshoots and variations of the earlier ethical views. In the light of this, it is not surprising that applied ethics has become what it currently is.

The primary function of academics in this field is the legitimatization of sectors, dimensions, and features of global capitalism. Bioethicists justify the work of the hospital and pharmaceutics industry by creating majority-accepted rules for its governance. Business ethicists justify perpetual economic growth by inventing models of sustainable development. Military ethicists justify the existence of the military-industrial complex by trying to make warfare more palatable by benevolent rules.

Is there anything else that we could do? As I see it, our alternatives include serving the system (this might be wise, as that is where the money and the power are); community-building (a search for neo-tribes); post-modern irony; a turn back to theoretical philosophy (only available to philosophers); and an endeavour to understand how the world works (for emancipatory purposes).

I welcome further suggestions on how to proceed and advice on what to recommend to students who wish to pursue a career in moral and political studies.

Taking reproductive obligations seriously

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A number of philosophers have argued that we have strong, positive reproductive obligations to try to ensure that we have the best child that we can have.

I, and many others have argued against this view on various grounds, including the indeterminacy of the concept of 'the best child'.

The present paper will, however for the sake of argument accept that we have these obligations and that they are justified by the reasons usually given in the literature, and will then proceed to an analysis of the weird and wonderful implications that follow from this view.

It will first be argued that my reproductive obligations has necessary implications for my choice of procreative partner, and further that my obligations necessarily extend to any reproduction over which I have causal control.

The first of these implications can potentially be blocked by invoking a right to 'reproductive liberty', but if such a right can regularly defeat reproductive obligations then these obligations must be very weak.

The consequences of the second implication will be discussed in detail, and it will be shown that it has very significant consequences for anyone involved in breeding animals, and that these cannot be

blocked by consideration of reproductive liberty, but only by accepting speciesism.

The final section will show that the proponent of strong reproductive obligations are on the horns of a dilemma where s/he will either have to accept that these obligations are weak and not strong, or accept a large number of very unpalatable consequences.

Should physicians help cross-border infertility patients evade the law of their own country?

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Europe is a patchwork of radically different national laws and policies on assisted reproduction. Many patients are crossing borders from restrictive to permissive states, facilitated by European laws on free movement of persons and services. These movements can be characterized as cross-border reproductive care (CBRC) for law evasion. This phenomenon confronts physicians in restrictive states with a moral dilemma: should they help patients who travel abroad to evade the law or not?

Until now, the role of the local physician in CBRC for law evasion has been described as ‘channelling local patients to foreign medical establishments’ and ‘against the spirit and essence of the law’. We

argue that this is a narrow view. CBRC for law evasion enhances reproductive autonomy for patients. This is only possible if they are adequately informed, to which end local physicians can play an important role. It is in the best interest of the patient to have a local physician to turn to during and after CBRC for law evasion. This diminishes the need for travel and the risks associated with complications, and it provides comfort and support.

With regard to informing the patient, we argue that it is not justifiable to intervene in the physician patient relationship, limiting what the physician can or cannot say, unless it can be shown that this intervention is in the best interest of the patient. With regard to the patient, withholding information is a clear violation of the principle of autonomy. It is also an indirect violation of the principle of justice because some people with more means or abilities will find out about the options abroad by other means while others cannot.

Empirical research on CBRC for law evasion has shown that some local physicians are willing to help patients game the system, allowing them to get reimbursed for part of the treatment. This is only justifiable if the health insurance system or the restrictive law is flawed. Otherwise gaming the system is a violation of the principle of justice.

The only argument that remains against an active role for local physicians in CBRC for law evasion is that by supporting CBRC for law evasion, physicians are essentially supporting immoral behaviour.

However, assisted reproduction is subject to a very high degree of moral pluralism, even within societies, so allowing CBRC for law evasion could be seen as a form of tolerance. Moreover, within Europe minimal standards are imposed to prevent unsafe and indisputably immoral practices. We conclude that the benefits of a supportive local physician outweigh the harms of supporting alternative ways to create a family.

"Dignity" and end-of-life decisions in England and France

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Dignity is one of the most controversial and yet commonly used term in debates regarding end-of-life issues. The term "dignity" can take various meanings. For example, it can be used to denote the respect owed to an individual person or to signify the intrinsic value of humankind as a whole. These two different understandings of dignity can inevitably lead to different approaches to end-of-life decision-making.

This paper explores the meaning of the term dignity in two European countries, England and France. Our philosophical and sociological analysis compares public debates and legislation on end-of-life related issues in these two countries. We will argue that in England dignity is

most commonly understood as respect for individual autonomy, whereas in France dignity usually signifies respect for human life in a broader, holistic sense. We will demonstrate that the difference in the conceptualisation of the term leads to different ethical, and hence legal and practical approaches to end-of-life issues and vulnerable patients. Our particular focus is on: (1) withdrawing/-holding life-sustaining treatment; (2) respect for patient preferences; and (3) assistance in dying.

Given the difference in the understanding of dignity, and the underlying philosophical approaches it feels that there is still a long way to go before we can establish common guidelines on end-of-life decisions across Europe and beyond. However clarifying the use of the term dignity in different discussions around Europe could hopefully facilitate this endeavour.

Democracy: the forgotten challenge for the development of bioethics in non-democratic countries

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Although seeking ethical standards for healthcare could be traced historically to thousands of years, exemplified by the Hippocratic Oath (5th century BC); the development of bioethics as a structured

discipline is quite recent. Bioethics in its current (taught and practiced) format has thrived in North America and Western Europe. Notably, most of the bioethics peer-reviewed journals and literature are produced from western philosophers and practitioners in comparison to other parts of the world.

In my presentation, I will present some figures in relation to the development of bioethics in the western hemisphere in comparison to other parts of the world. These figures will specifically present some comparison in terms of ethics guidelines, journals, and literature published in peer-reviewed journals.

I will also argue that the steps ahead that the western hemisphere philosophers and practitioners in the contribution to the development of the field can be mostly explained by three main factors. First, there are comparatively advanced and complex healthcare systems, which give rise to more ethical issues than less sophisticated systems. Second, there is the development in the rights-based legal system. Lastly, there is a fairly longer history of well-established political regimes that came through democratic processes. I have not included the possible factor of reduced capacity of the researchers in non-western countries, as it is beyond the focus of this presentation.

In this presentation, I will focus on the latter factor – democracy, as a clear example of the link between bioethics and politics. I argue that it is not possible to anticipate true development of bioethics without freedom of speech, and freedom of expression of opinions within a

legal system that empowers the power of the communities to hold their governing authorities accountable for their decisions and policies. I will give examples from the context of some non-democratically ruled developing countries.
In the last part of my presentation, I will propose some steps that could be done to help the development of bioethics in such countries where the basic freedoms are absent.

Robots and the division of care

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Care robots are being developed to support frail older people to live independently in their own homes. Consideration must be given to their place in the division of responsibility between formal carers (healthcare workers who are paid to provide care) and informal carers (usually relatives or friends of the older person who are unpaid). Formal carers may wish to have control over a patient's care so that they can discharge their duties efficiently, but this may conflict with how informal carers wish to discharge their perceived obligation towards their older friend/relative. The patients themselves may also justifiably wish to have some say in how their care is delivered, and

recent political emphasis on 'patient-led' care may make them even more central to this discussion.[1].

A crucial aspect of the power struggle between these four parties is the control of, and access to, information about the patient. Older people may understandably wish to keep information about their health private, either from their friends/relatives, from formal carers, or both. Conflicts may arise if one party is privy to information that another is not, as knowledge about the older person may influence the way in which these groups think care should be given, or even whether they are willing to provide care at all. When a care robot is introduced, there is the added complication of how *it* should use information, and whether there are certain things that it should flag to formal or informal carers. How the robot has acquired the information also matters, since it may not be possible for the older person to disable a robot's monitoring capabilities on occasions when privacy is sought. Rather, there may be agreements or assumptions made about control over whether, and by whom, this information is accessed.

This paper will present some findings from a qualitative study, which used focus groups in the UK, France, and the Netherlands to explore the views of formal carers, informal carers, and older people about the ethical issues surrounding the introduction of robotic carers into elderly people's homes. These findings speak directly to the ethical issues described above. For example, older people reported greater willingness to divulge information to healthcare professionals than to

relatives, and formal carers also expressed a reluctance to let informal carers be party to information. Informal carers may, however, assume that they will be included in discussions about how care is provided. This may arise from concern for the older person, but also because they are part of the care team and these decisions therefore affect them. This raises important questions about the extent to which robots should be viewed as (extensions of) healthcare professionals, or as companions to the elderly, and how much information different parties can access via the robot. The paper will conclude with some tentative suggestions about how these problems should be negotiated.

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Information, Consent, and Research with Humans: A Qualitative Study on Clinical Trial Participants' Use of Information Sheets

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Patients' participation in clinical trials is essential for determining the efficacy of new medicines and medical products, helping to broaden medical knowledge. There is evidence that being given large amounts of information about trials deters patients from participating in these trials.[1] It is also important that research participants are properly informed when they decide to participate in trials. We know, however, that they do not read much of the information given to them.[2] This creates an ethical issue in an environment where *informed* consent is valued highly and even deemed necessary for the justifiable use of humans as research participants. Medical research is certainly one such environment, dating back to the Nuremberg Code, which emphasised participants' 'sufficient knowledge and comprehension of the elements of the subject matter involved' as a necessary condition for consent.[3] More recently, the importance of information in consent has been codified in the Declaration of Helsinki,[4] the EU Clinical Trials Directive (2001/20/EC), and in the UK, the Medicines for Human Use (Clinical Trials) Regulation 2004.

This paper will present the results of a qualitative, pilot study, which seeks to gain a snapshot understanding of patients' use of both

information sheets and "consent interviews" (meetings with trial team members to discuss participation and record the patient's consent to participate). The study makes use of observations of these consent interviews, and interviews with both recently consented trial participants and participants at a follow-up stage, aiming to either support or disconfirm the usefulness of a larger study in the future that will explore this area in greater detail, with an overall aim of improving the provision of information to potential trial participants.

Following the presentation of these results, the paper will argue that the importance of informing participants is mainly independent of consent, and that the importance of consent itself is widely overstated in discussions of medical research ethics. To achieve this, the paper will outline a philosophical criticism of the notion of consent, arguing that while the currently popular absolute side-constraints against certain types of research without consent are intuitively appealing, they fail to account for large-scale future benefits that such research could bring.[5] As a way of bringing these potentially controversial considerations closer to quotidian intuitions and moral feelings, the paper will point to the everyday use of nonhuman animals in medical research, whose use is justified in terms of the far-reaching and overall good that it will create. The paper thus makes the overall suggestion that deontological requirements for consent are often introduced too quickly, and that current policy and practice may have serious difficulty reconciling the concurrent aims of conferring

medical benefit and of protecting individuals. Following this, it is deemed that the value of information is not in supporting consent, but in the benefit for participants of knowing about the research.

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[2] Antoniou, E., Draper, H., Reed, K., Burls, A., Southwood, T. and Zeegers, M. (2011) An empirical study on the preferred size of the participant information sheet in research. *Journal of Medical Ethics*, 37, pp.559-562; Kirkby, H., Calvert, M., McManus, R. and Draper, H (2013) Informing potential participants about research: observational study with an embedded randomized controlled trial. *PLoS ONE*, 8(10): e76435

[3] (1996) The Nuremberg Code (1947). *BMJ*, 313: 1448.1

[4] World Medical Association (2013) Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects [online]. Available from http://www.wma.net/en/30publications/10policies/b3/ [Accessed 27 February 2013]

[5] Harris, J. (2005) Scientific research is a moral duty. *Journal of Medical Ethics*, 31 (4), pp. 242-248

Real-biopolitics – pharmaceutical companies and conflicts of interests

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Biopolitics is a fascinating issue, which, so far, was mainly described by post-structural philosophers. I would like to examine this concept from different perspective - the perspective of political realism. I will analyze the connections between medicine and power using the language, which is closer to Hans Morgenthau's theory than to the terminology of Foucault. I want to analyze the relation between bioethics and biopolitics on the example of pharmaceutical business.
How can we describe pharmaceutical industry in terms of biopolitics? Can we look at the pharmaceutical companies as at political players?

What kind of powers do they have? Can we consider for example the right to determine the price of drugs as a sort of political power?

The problem of price of drugs is linked with the question of justice in healthcare. I would like to concentrate on the issue of socioeconomic status and access to medications. Is there a significant difference between the actual price of drugs and just price of drugs? Does patent law work against the idea of justice? I'm going to analyze the arguments against the state regulation of drug price. Is there a clear conflict of interests between state, patients and pharmaceutical industry? Are there any political interests hiding behind bioethics regulatory decisions?

Another problem I would like to discuss is the marketing of drugs. I'm going to analyze the phenomenon of drug advertisement as a sort of control over society. Are there any social groups, which are especially susceptible to the power of advertisement? What are the stereotypes or social expectations that might be reflected in drug advertisement? Does the drug advertisement "produce" new diseases?

I want to examine those problems from realistic perspective, asking if there is a place for bioethics in the pharmaceutical logic of profit.

Ethics Training for Healthcare Professionals working in the field of Infectious Disease Control

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Healthcare professionals who work in the field of infectious disease control are often confronted with ethical dilemmas. The classic problems are questions concerning quarantine, isolation and mandatory treatment, which are related to the underlying issue of individual liberty and autonomy versus public interests. In daily practice however, interventions as quarantine, isolation or mandatory treatment are hardly ever used. The ethical debate here concerns far less intrusive measures. Although the interventions used in daily practice are less intervenient, they nonetheless address the same issue of individual liberties and the common good. Daily practice may therefore also benefit from systematic ethical reflection.

Various tools have been developed for moral case deliberation in medical practice. The moral problems raised by daily practice of infectious disease control however extend beyond the ethical arena of medical ethics, where patient autonomy and informed consent are usually point of focus. Professionals working in the field of infectious diseases need to place their ethical reflection in the context of public health and the common good. The methods that are used for moral deliberation in medical ethics are therefore not always suitable for

reflection in this specialized field. In a collective project of The Ethics Institute of Utrecht University and the Municipal Health Service of the Middle Netherlands we have explored the variety of common moral problems in infectious disease control. We have developed a method to analyse those problems and started an ethics training for teams of infectious disease control professionals to apply this method in moral case deliberation.

We would like to present our experiences with the ethics training and show the method to analyse moral problems in the field of infectious disease control.

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PM as technological mediation: constituting new identities and restructuring relationships through changing medical practices

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Comprised in the vision of Personalised Medicine (PM) is the expectation that a wide range of new technologies will drive through and facilitate the personalised form of healthcare. However, studies in the philosophy of technology and in Science and Technology Studies point to problems in assuming such a straightforward connection between the development and implementation stages of innovation. The actual impact technologies have on their designated practices can be surprising from the design and development perspective. Surprising both because the technologies might have a different functional impact than intended, and because the technologies might influence other, non-functional aspects of the practices, which were not taken into consideration in the development. Among other problems, both types of surprise make it difficult to anticipate which ethical issues that might surface from re-structuring an existing practice around a new technology. In this talk I shall focus on the latter type of impact, more precisely how the technologies of PM will challenge existing identities, roles in healthcare, and the relationships that patients have to healthcare professionals, informal caregivers, and to society at large. I will do this through regarding PM as a case of *technological mediation*, a theory about the human-world relation when it is mediated by technology. First, I shall present the main concepts of this theory, focussing mainly on how technologies contribute to constitute subjecthood, and then ask if the theory might contribute to broaden

the basis for our anticipation and assessment of the impending transformation of healthcare coming from PM.

Biopolitics – the role and potential of pacients' organisations

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The formal and informal creation of self-help patients' groups has always been an important part of healthcare: they provide psychological and social support for the ill and their care-givers. Since the end of the last century, the work and official position of patients' organisations has changed considerably. This is due in part to the enormous progress made in medical technologies and problems that have consequently emerged (increasing healthcare expenditure, excessive medical specialisation, dehumanisation, commercialisation, etc) and the democratisation of society (predefined roles, patient power and status), which have meant that patients have become clients, and in some cases consumers – there is even a patients' organisation called International Consumer Support for Infertility. Patients' groups are becoming official organisations, part of national and international networks. They are autonomous political entities seeking to alter the kind of healthcare on offer. In 1999, for instance, the International Alliance of Patients' Organizations (IAPO) was founded which 'advocat[es] internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies; Building cross-sector alliances and working collaboratively

with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives'. In 2003 the European Patients Forum (EPF) was founded to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU. IAPO mainly seeks to influence policy within the World Health Organisation, while EPF is focused on the European level. In fact, 'EPF should be seen as a response to recent calls by the European Commission and other EU institutions to have one pan-European patient body to address and be consulted on issues concerning the interests of patients in the European healthcare debate'.[1]

The presenters are active in patients' organisations at both the regional and international level. Our engagement is primarily motivated by the need to provide psychological and social support to patients. Being engaged in international projects has led us to grapple with a number of ethical issues, concerning for example doctor/patient relationships, patient narratives, the role of patients' organisations as a political force, the role of the medical professions, patient-centred healthcare, patients' organisations and policy-making.

[1]See www.eu-patient.eu/Documents/Who%20we%20are/CoreDocuments/EPF_declaration.pdf

Red wine as a placebo – the ethics of placebo use in twenty-first century medicine

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In autumn 2013 Czech experts working in the field of medically assisted reproduction (MAR) officially recommended that patients suffering from infertility should take dietary supplements to improve their fertility. Specifically, they recommended that women should drink Bona Dea red wine, rich in the natural anti-oxidant resveratrol (arguing that it should be sold in chemists'), and that men should take Reproman tablets. In neither case is there any evidence to suggest efficacy, and of course patients have to pay for the supplements out of their own pocket. The question therefore arises as to the ethical nature of recommendations of this kind.

In ancient medicine and in medieval Christian and Muslim medicine, working with the patient's mental state occupied a central position in medical morality. The Hippocratic conception of medicine attempts to explain disease on a purely rational basis, which may have led medicine to where it is today, but has not denied spiritual healing its successes. The development of the patients' rights movement and the decline of the paternalistic paradigm have gradually led to the prevailing belief that the use of placebos to pacify patients is a

deliberate attempt to deceive patients and has come to be viewed in much the same way as ‘white lies’. Like white lies, the use of placebos ‘interferes’ with patients’ rights to a variety of information about their medical states. The clinical use of placebos also poses problems relating to informed patient consent and patients’ rights to see their medical records. However, it has also been shown that traditional criticisms against the use of placebos favour a strictly biological view of disease and sideline mental, social and spiritual dimensions, including the trust-based therapeutic relationship between doctor and patient, and faith in the effectiveness of the medical approach. The predicament of biomedicine and the deliberate animosity of the pharmaceutical industry and evidence-based medicine towards spiritual healing, in evidence since the 1970s, have created tension and there are also ethical and social issues to be considered.

Human beings have lower fertility rates. The norm is that pregnancy occurs after a year of trying (until recently two years of trying). Unsuccessful attempts are, however, very stressful and media portrayals of the success of MAR create the impression that the success will be achieve within a short period of time. Consequently couples sometimes seek assisted reproduction after only a few months of trying. Therefore, in order to prevent premature, uneconomical and also unethical invasive treatments, some countries (e.g. the Netherlands) have created strict guidelines as to how to diagnose

infertility and when to intervene. Having to wait passively, however, substantially increases mental distress in those longing for a baby. It may be that stress can be reduced if recommendations are made as to ways in which fertility can be improved – such as through the use of dietary supplements.

In recent years, the question has once again emerged as to whether placebos should be used in postmodern medicine. We argue that placebos may have a role to play under certain circumstances: 1. The dietary supplement has been tested and all regulations are adhered to. 2. The doctor who recommends the placebo does not profit from the recommendation. 3. The recommendation is made on an individual basis, as part of the doctor-patient relationship, and is not made on a wide scale or publicly announced by a specialist institution.

Obligations of International Organizations under International Biomedical Law - New Approach to Global Bioethics

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Intergovernmental organizations should unquestionably play a vital role in the global bioethics and biopolitics. The necessary basis for the institutional and legal framework, in which they would operate, could be found in international biomedical law. International biomedical

law, as a new branch of international law, established itself on the foundations laid by international human rights law and allows international society a clear view of where bioethical problems lie in modern society. However, taking into consideration classic relations between states and international organizations, it may seem that this role could only be of secondary nature, raising serious questions about their effectiveness. In my presentations, I would like to focus on the nature of obligations and duties of international organizations found in international biomedical law. The states purposely situated these organizations within the international legal order and so it should enhance their legitimacy and increase their effectiveness. Using international legal theory, I will analyze how the obligations of international organizations develop and how we can justify their obligatory character. Describing and acknowledging the underlying principles governing the activities of intergovernmental organizations that stem from international law and international human rights law could enable us to look at international biopolitics form a different perspective. This new outlook on international legal system would mean that activities of international organizations would no longer be only discretionary but should be recognized and reinforced within the international society. This new approach to the international governance of bioethics could help us identify the most basic principles of international biomedical law, principles that are not just an abstract legal concept but a reflection of values represented by

international actors. In my presentation I will also focus on the correlation between the obligations of international organizations and states that create them. I would argue that any legal activity and the resulting acts of intergovernmental organizations should be taken into considerations by the member states, not only because of the political or ethical obligation but mostly because of the legal obligation stemming from the principles of public international law. This new approach to global bioethics could mean that intergovernmental organizations, as international legal entities, are subjects to the obligations of international biomedical law and the rights conferred upon it. It could also mean that their autonomy grants them the right to act on the behalf of the particular or all member states, which potentially could change global biopolitics.

Empowered by choice?

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At the heart of the new genetics is the right to choose which is predicated on the right to information, and other relevant resources, to enable a choice to be made. In many areas of everyday life choices have proliferated, from TV channels to ways of serving coffee. Many consumer choices will be trivial but patients and parents are also

increasingly bombarded with information and advice on matters concerning health and child rearing, accompanied by more or less subtle messages about what the good parent or the responsible person should do.

Choice alone, even in the absence of economic costs, does not ensure equality. In health care, and others areas like education, the active, information seeking, articulate parent or patient is both a problem, because their success in getting the best service impacts on others, and the model to emulate.

It is frequently assumed that the individual will be empowered by choice, in the sense of having increased control and autonomy. This paper first discusses the choice agenda in general and the effects of choice on the chooser. Next, the reality of (parental) choice is discussed in relation to the genetic screening of embryos and children. In practice choices are limited to accepting or refusing the tests that are offered and the parent (or prospective parent) will bear the responsibility for the outcome of these choices. In specific circumstances choice can be a burden from which people would like to be relieved, can lead to stress and confusion or, if the available choices do not meet expectations, to disappointment and regret. In this context choice and individual autonomy seem to be an insubstantial ethical framework that increases responsibilities but does not empower unless we have the means to choose well.

Spiritual Needs at the End-of-life

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People often begin to realize the transience of life and think about the meaning of dying when someone from their loved ones is in danger of death. They start to think about the problems that have not been resolved and can affect the internal balance and suffering of the patient. Especially in a state of spiritual distress defined as one of the nursing diagnoses related to the issue of spirituality. It such state the individual actually or potentially impaired the faith, the system of values that provide the strength, hope and purpose in life.

According to O'Brien (p.106-107, 1982) has spiritual distress following symptoms:

- Spiritual pain - related to reconciliation with the loss of a loved one, or great suffering
- Spiritual alienation - alleging from separation from the religious community, family and loved ones
- Spiritual anguish - encompassing the doubts of opinion or value system and uncertainty
- Spiritual guilt - emanating from failure in faithfulness to religious rules
- Spiritual anger - based on difficulty accepting the disease or suffering

- Spiritual loss - comprising difficulty finding comfort in religion, lost of peace and sulk
- Spiritual despair - lack of interest leading to a resignation

*Methods – questionnaires***:**

180 questionnaires distributed, 175 returned, 97% return.

In survey, we focused on next problems:

1. Health care workers and the spiritual needs of patients.
2. Reason to satisfy spiritual needs of patients.
3. Deficiencies in meeting the spiritual needs of the dying.

*Timing and reason***:** from January to March 2013 as a part of project KEGA034-KU-4/2013: "*Meeting the spiritual needs of dying patients in terms of health care workers in terms of practice"*

*Places - institutions***:** Central Military Hospital Ružomberok – Faculty Hospital, National Institute of Tuberculosis, Pulmonary and Chest Surgery in Vyšné Hágy, Hospital in Liptovský Mikuláš and individually interviewed health care workers.

Results: 75% of respondents saw spiritual needs as the most important in dying patient, 11% uderlined psychological needs, 11% biological needs and only 3% social needs. According to the observations of respondents 42% of all patients at the end-of-life stage linked spiritual needs with the hope in eternel life, but between religuious patient it was 83% , 29% of all patients to the lost of earthly attachement – in religious patients 66%, 22% to the believ in spiritual dimension of human being - 21% in the group of religious patients, and rest 7% and

5% didn´t answer. When assessing the attitudes of health workers, we found that 63% agree that is necessary to meet spiritual needs for dying patient, 26% only if patient or family is asking for it, 9% didn´t answer and 2% expressed opposition. Respondents reported the following methods -ways of meeting spiritual needs: 36% visit of the priest and Anointing of the Sick, 25% empathy of present community, 25% prayer and 14% symbols and gestures. The most common shortcomings in the meeting of spiritual needs were: 67% lack of time, 18% attitude of the stuff – it is not important and 15% didn´t answer.

*Conclusion***:** Based on the findings, we can conclude that priority needs in life can be changed, but the final stage of life is dominated by spiritual needs. As each human being is original, unique and has his mission here on earth, such unique is also his dying and death.

Are Non-Heart-Beating Organ Donors Dead?

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Successful organ donation requires well-preserved organs. However, the “dead donor” rule restricts the removal of vital organs from living persons. While most vital organ transplants come from donors who have been declared dead based on the neurological criterion of

determining death, i.e., total brain failure, some vital organs come from non-heart-beating donors that are thought to satisfy the traditional criteria for determining death, namely, the irreversible loss of circulation and respiration. Under current protocols involving such donors, the transplant team will wait anywhere from 75 seconds to five minutes of asystole before removing organs. However, critics of such protocols, such as Joanne Lynn, Robert Veatch, and Don Marquis, question whether the cessation of circulation and respiration in these donors is truly "irreversible." In their view, because of the possibility of spontaneous auto-resuscitation and the fact that we could intervene to artificially resuscitate these donors, the potential for the resumption of their functions still exists. Consequently, these critics argue that the donors have not satisfied the "irreversibility" requirement in the circulatory and respiratory criterion for determining death and thus removing their vital organs violates the "dead donor" rule. This paper examines what "irreversibility" means in this context? Must we wait until it would be impossible to restart the heart (perhaps because the donor has become whole brain dead)? Or can we declare death both quickly and ethically?

Should the bell toll for the research-care distinction in biomedical ethics?

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The aim of the presentation is to revisit the research-care distinction and to find arguments for defending it in spite of the recent criticism. More than thirty years ago the biomedical ethics was bifurcated into research and practice/clinical care. The former governed interventions that are designed solely to benefit the well-being of an individual patient, whereas research was understood as an activity designed to test a hypothesis, to permit conclusions to be drawn and to develop or contribute to generalizable knowledge. Most prominently, the Belmont Report from 1979 set the stage for how to protect human subjects in research and how to enable physicians to do research without violating the duty of care.

First I will look briefly at the history of biomedical ethics and at the main frameworks and notions used most commonly until now. I am mostly interested in finding out what were the reasons for the introduction of the bifurcation and in whose perspective it was good and necessary to have such a distinction.

Secondly I will look at the recent criticisms of the distinction (for example fuzziness of the distinction, oversight burdens) by prominent scholars (e.g. Ruth F. Faden et al). In forming our opinion about the

distinction and its role we should take into account the latest developments in the field of 'omics', issues related to biological material, personal data, feedback etc., which were not relevant at the time of the bifurcation.

Thirdly I will ask whether this recent critique is relevant and justified? In order to answer these questions I will look at four examples – randomized clinical trials, human research in disasters, research on biological material and personal data, quality improvement/public health/epidemiological research. These cases will be analyzed by imagining how would the life of researchers and participants look like without this delineation? What would other possible alternatives look like and what could guide us to the duties of researchers?

Finally, I'll conclude by arguing that despite important changes in biomedicine over the last decades, there are still significant reasons for not sounding the bell for the research-clinical care distinction.

The biopolitics of assisted suicide: the case of Switzerland

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In contemporary democracies, active aid in dying (euthanasia, assisted suicide) is typically discussed as a matter of medical ethics and medical law. In liberal jurisdictions - those which authorise euthanasia

or assisted suicide or both - this turns into a conversation on the proper judicial oversight of these practices, their compatibility with the medical ethos (however defined), and the kinds of requests for aid in dying that are, or should be, deemed acceptable. The eminently political dimension of aid in dying is less apparent in contemporary bioethics than are issues focused on individual conscience and the private sphere. Yet these issues are connected to paradigmatic biopolitical issues such as the authority over life and death, either at the hands of government (historically this involved mainly capital punishment and the criminalization of suicide for political reasons), or within the personal authority of individuals over themselves in the liberal polity.

The Swiss practice of legal assisted suicide harks back more directly to these biopolitical questions than is the case in other liberal countries. The main reason is that in Switzerland, the legalization of altruistic assisted suicide did not result from "modern" debates about patient autonomy at the end of life, as was the case in other liberal countries. Rather, it occurred much earlier and was rooted in legal and political reflection on voluntary death that resulted from decriminalizing suicide itself. This started an ongoing discussion of the right to choose the time and manner of one's death that still has relevance today, well beyond the borders of Switzerland as exemplified by recent decisions of the European Court of Human Rights (e.g. *Pretty vs. UK, 2002*). Also, Swiss law does not require

participation of a physician in suicide assistance, and in practice this is often provided by lay organisations. This has induced a critical discussion of medicalization of aid in dying, a discussion that is much less prominent in other liberal countries.

We believe that the Swiss system of assisted suicide provides a "philosophical microscope" that allows a fine-grained analysis of the liberties, claims, and rights that contribute to the normative landscape of liberal democracies as regards the right to die. Our analysis focuses on formal and informal norms that are relevant both to the request and to the provision of suicide assistance. It also examines critically the legitimizing force of medical discourse as regards not just assisted suicide but active aid in dying generally. This is especially interesting in a context where medical involvement is not seen as axiomatic, but represents a pragmatic necessity linked to the prescription of lethal controlled substances. Three distinctive medical discourses are examined, one that regulates access to active aid in dying through the certification of a diagnosis; one that defines which sorts of diagnoses can legitimize such access; and one that invokes medical expertise to assess decision-making capability. Each is based on rather different philosophical and biopolitical presuppositions.

Repoliticising Health

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Health, especially public health, is often seen as a matter of primarily scientific involvement. Health problems are researched and the best health measures and policies are formulated, which leaves implementation as the sole task for professionals, authorities and other actors carrying responsibility. Uncertainty may be acknowledged, but only regarding factual developments, i.e. 'cognitive uncertainty'. This way, health is effectively taken out of the realm of politics and framed as a technological and managerial problem: it is depoliticised.

However, in society as well as in philosophy there are many differing interpretations of health and its value and goal: there is also 'normative uncertainty'. Such value dissensus has potentially far-reaching consequences for both the evidence as produced by the health sciences as well as for health policies and politicians. How to deal with that?

Within the 2014 Public Health Status and Foresight (PHSF) of the Dutch National Institute for Public Health and the Environment (RIVM), we decided to take this normative uncertainty serious. Based on stakeholder sessions, we were able to define four sets of values, motives and challenges within public health. These were combined with strategies containing policies and concrete actions into four

different scenarios for the future of public health: -In the Pink of Health: a long life in good health; -Everyone Takes Part: social participation and equity; -Steering your own Life: autonomy of citizens and patients: and, -Healthy Wealthy: sustainability of health care expenditures (titles tentative). Each scenario can each be seen as an answer to this question: what is important in public health and its policy, what kind of evidence is needed and valid, what should be done by whom, and based on what values? Confronting and combining these four different scenarios contributes to public health policy by identifying: -opportunities if one scenario strategy solves public health challenges including those from other scenarios; -dilemmas if a specific scenario strategy is good for one challenge, but worsens another challenge from different scenario.

This way, the PHSF contributes to making health and health policy again political, i.e. an issue in which values regarding the good life and the good living together necessarily and rightfully play a role. Using such scenarios instead of the common 'evidence-based'-discourse -which in fact often favours a medical technological perspective - does more justice to the many voices and experiences surrounding health, and to the many different values in society. Thus, repoliticising health may also lead to more effective policy with better connection to society and its professionals.

How can the deliberative process turn the perspectives?

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At the University Hospital of Aalborg, in the northern part of Denmark, we have had a Local Clinical Ethics Committee (CEC) since January 2008. We were among the first hospitals in Denmark, which initiated ethical analyses and deliberation of ethical dilemmas reported from the clinical activity at the hospital. And it is the role for a Local Clinical Ethics Committee, to deliberate or facilitate an ethical refection with the clinicians, - it is not to affect the politicians or to be part of the policy-making process. For that purpose we have a national board called "Etisk Råd".

In an oral presentation I would like to present how we work in our Local Clinical Ethics Committee, which method we use, how the process is structured, and how we make sure, that the process is deliberative and not becomes a discussion among the participants.

After having presented the method and the theoretical background, examples will be given from the bioethical reflection, and how the process has turned the clinician's perspective or given the clinicians a new look on the patient's situation.

Can there be post-persons and what we can learn from considering their possibility?

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In one of the liveliest discussions concerning the prospects of human enhancement number of bioethicists recently have considered the possibility of creating beings whose moral status is higher than that of (mere) persons (Buchanan, 2009, Agar, 2013, Douglas, 2013, etc). For example, Nicholas Agar in his recent paper "Why is it possible to enhance moral status and why doing so is wrong?" has argued for two claims, first, that post-persons, beings whose moral status is superior to that of persons are possible and, second, that creating such beings would be wrong. The main purpose of Agar's paper is to show that there are good moral reasons not to produce humans that are enhanced beyond certain limit. However, I want to address Agar's first claim on the possibility of post- or supra persons. In particular, I intend to question the assumption made by Agar (an others) that being's higher moral status by itself implies the recognition of this status by others. I will also try to show that this discussion should suggest the necessity to reconsider some assumptions on which much of the recent literature on human cognitive enhancement relies.

Palliative sedation therapy and assisted suicide: a distinction that still makes sense?

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Palliative sedation therapy (PST) is an important clinical ethics issue in a physician's daily practice. In many countries, PST is considered an ethically distinct from assisted suicide (AS). But even regarding PST there are ethical controversies in the literature. In addition the differences between these two practices can be veiled under certain circumstances. In this context does this ethical distinction still make sense? Under which conditions? The contribution aims to provide an appropriate response to this question.

The "Grey Area" of Informed Consent: An Analysis of the Capacity to Consent Specifically of People with Dementia

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Decision-making capacity and informed consent is at the core of any therapeutic or medical research activity, ensuring that the ethical norm of respect for the autonomy of a person is duly considered. The recent increase in the prevalence of people with dementia (PwD) poses a

special challenge for all three aspects of the classic definition of valid informed consent: competence, disclosure, and voluntariness (Beauchamp & Childress, 2009). Schneider and Bramstedt (2006) discussed differing practices and understandings of informed consent between psychiatric (e.g. regulation-based) and bioethical disciplines, resulting in two separate notions of capacity to give valid informed consent. It triggered an ethical debate about the understanding of valid informed consent as a singular legal act, and the interpretation of informed consent as a part of an individual's authentic personal narrative (Bowman 2008). Various approaches have been explored to define alternative ethical interpretations of informed consent in the case of PwDs. My presentation will provide an overview of the advantages and disadvantages of these interpretations, focusing on the "grey area" of informed consent with regard to the specific conditions of PwDs.

Should Conditional Organ Donation be allowed?

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In June 1998 in England, a controversial incident took place. A transplantation team accepted organs from a deceased donor whose family demanded that they must go to a white recipient. The lives of

several people were saved thanks to this controversial gift, however team's proceedings were criticized by a panel established to investigate this case. It was asserted that to attach any condition to a donation was unacceptable, because it offended against the fundamental principle that organs are donated altruistic and should go to those patients in the greatest need.

The British Department of Health's definite condemnation of conditional donation was considered too radical by some ethicists. T. M. Wilkinson argues for the acceptance of the conditional organ donation regardless of the conditions set by donor or her family. His arguments deny the panel's rationale for the prohibition of conditional donation. Firstly, permission of only altruistic donation is put into question. After all, an altruistic system of acquisition and allocation of organs should strive for the best efficiency in meeting demand for organs. Yet, reducing the number of obtained organs to those that are offered altruistically does not meets this condition. Wilkinson's second argument has similar scheme. Here it also is pointed out that the realization of certain goal can be more efficient using indirect methods than direct. This argument undermines the principle according to which organs should be allocated firstly to those in greatest need. In Wilkinson's opinion, the goal of meeting demand for organs most efficiently justifies that principle. However this goal can be more effectively acquired when conditional organ donation is allowed than

if this goal is «typed» in to the content of the rule governing allocation.

The main task of my presentation will be to challenge Wilkinson's argumentation as well as defend the British Department of Health's position, which might equally as well serve as a justification of existing regulations in Poland.

The political and ethical dimensions of inclusion - a case study based upon the Mental Health (Care and Treatment) (Scotland) Act 2003

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The paper addresses the core theme of the conference – the relationship between Bioethics and Biopolitics – by reflecting on the processes involved in the formulation of Scottish Law on Mental Health care and treatment. Mental health legislation purports to safeguard the well-being of some of the most vulnerable in our society. Those responsible for drafting mental health legislation are required strike a delicate balance between promoting the autonomy of those who may receive a diagnosis of one or more forms of mental disorder, and the need to restrict or limit that autonomy either for the protection of the individual or society as a whole. The Mental Health

(Care and Treatment) (Scotland) Act 2003 has been widely heralded as representing the gold standard of such legislation and held up as an example for other jurisdictions to emulate. This legislation contains three categories of mental disorder namely: mental illness, learning disability and personality disorder. This legislation adopted a principle-based approach, not least by explicitly drawing upon the four principles approach outlined by Beauchamp and Childress to provide an underlying bioethical structure for mental health legislation in Scotland. On the face of it the inclusion of those who attract a diagnosis of personality disorder represents a form of progress, insofar as it provides a means for those who fall within this historically marginalised diagnostic group, to assert their right to both recognition and appropriate service provision. In this sense one might think that the process is one, which embodies all that is best in bioethical thinking.

However, closer examination of the underlying policy process suggests that the decision to explicitly include the category of personality disorder was a response to a moral panic, and the need for politicians within the newly established devolved Parliament in Scotland to be seen to be in control of events rather than controlled by them. The apparent inclusion of those who fall within this diagnostic group is consequently limited and contradictory in that they continue to be marginalised and overlooked within key aspects of the policy framework that drives practice on the ground and shapes the way that

services are designed and delivered. The Mental Health (Care and Treatment) (Scotland) Act 2003 is an example of the limits of legalism representing at most an example of symbolic legislation that is ultimately less intended to advance the public good than to accommodate competing interests. Despite the fact that a right to mental health services has been long acknowledged in international agreements since the mid-20th century, exemplified by the United Nations Covenant on Economic, Social and Cultural Rights, the legitimate needs of those who fall within the diagnostic circumference of personality disorder in Scotland continue to be subservient to broader political considerations.

Individuating medicine and big science structures

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Systems biology is often presented as a key research field for medical attempts to target treatments for individuals or groups of people. The field epitomize current expectations of enhancing understandings of individual human biology by computational means. This paper draw attention to the nature of the sciences enabling this medical vision: individuating medicine call for large material and social infrastructures. The paper aim at clarifying the ethos of personalised

medicine as big science by focusing on areas where the epistemic work of building infrastructures intersects with bioethical issues.

Bioethics and Biopolitics: their common denominator

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The first obvious thing that the two fields have in common is the prefix "bio" in their names. "Bio"-as we know- derives from the Greek word *bios, which*, alongside the other Greek word *zoe*, they denote life. However, "bio" conflates the distinction between the intellectual and public life of a person and the corporeal life, which is evident in the use the two Greek words. The question is to what extent the two fields incorporate the two meanings of "bio" and address the distinct issues and problems that arise and which reflect the highly contested dualism of the physical and the mental in human conduct.
The second thing that the two fields share is that they both address moral problems and participate in shaping the conduct of individuals and policies of social groups. The problem in this fusion of the public and the private domains is that in the public domain policies and laws are the product of negotiation public deliberations, elections or even the exercise of power whereas moral principles are formulated by social processes and personal attitudes which are put to the test of

reason. Further, the violation of laws is followed by specific punishments, something that is not the case in the violations of moral principles.

Bioethics and biopolitics derive from ethics, which constitutes their denominator but their choice and the application of the moral principles ranges from being simply different to being outright contradictory.

Emerging Technologies and Ethics: which integration and management in health care policies?

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Technological development which, in various fields of science and medicine, has reached extraordinary progress in achieving a great amount of new knowledge and information regarding people-patients, shows an apparent "paradox". On the one hand there is the autonomy of research and its sectorialisation, and, on the other, a urgent need for convergence and integration. All this entails benefits and criticalities, especially in the medical and health care fields, since are the same population and the same individuals to be studied and compared. Hence, there emerge ethical and managerial issues that challenge

institutions, agencies and social health authorities, as well as policy-makers.

These are the premises that, in Padua, gave birth to 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 (neuroscience, nanotechnology, genetics, computer science, etc...) in the medical-clinical field so to achieve a global management of the overall health of the individual within the community and its environment. The research responds to the need and novelty, at least in Italy, but also in a European perspective, to promote an effort aiming to address the ethical issues of such an integrated approach to the various technologies involved, closely working with the local health institutions. The interdisciplinary group is complemented by a "laboratory" represented by the population of the local Local Health Unit in order to identify and verify in the field the ethical issues derived from the use of these technologies in health care. The perspective 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, genetic bands, nanotechnology and neuroscience concerning the individual. We need to deal with: the value of data, privacy, priorities and urgent health needs of the population, prevention campaigns, therapeutic and personalized approaches, intervention planning and

resources allocation. This paper presents the results of the first work phase of the study group aforementioned.

Is there good justification for research involving children?

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Although research involving children is currently universally accepted scientific and clinical practice, it might raise some ethical doubts. If some children are involved in research because, without such research children in general would be deprived from safe and proven therapy, one may ask a question, whether we do not instrumentalize participating children. To sufficiently justify involving children in biomedical research many arguments are given. Some argue that there is a moral obligation to participate in biomedical research, especially if one enjoys the results of development of medicine. In that sense a child should participate in generating of important social good: safe and effective medicine. Second way to justify children participation refers to the nature of parental relationship. The relation between parent and children has a very intimate and private nature. Because children are not able to make choices on their own, their parents act on their behalf according to their values and belief. Therefore if parents believe that participation in biomedical research is a morally

praiseworthy activity they have right to enroll their child into clinical research. Their choice is protected by the right to privacy and can be overruled only when it is proven that they expose their child to undue risk. Finally one can justify children participation in biomedical research proving that involvement in biomedical research is in a child's best interests: for instance in the future participation in biomedical research might be realized by a child as an important part of her life-narrative. But none of these justifications is sufficient. The main reason is an ontological and existential character of being a child. Being a child is becoming an autonomous person. A person who is becoming cannot be subject of certain moral obligation, cannot take full responsibility for herself, but on the other hand also she has her own interests. A complex of existential situation of being a child has two important consequences. Firstly, it is very difficult to get rid of intuition that children are actually instrumentalized in biomedical research. Secondly, regulations concerning research involving children should reflect complexity of child's existential situation. Regulation should rather allow balancing interests of a child, parents' beliefs, developing autonomy of a child and interests of society than overstress one factor, for instance parents' beliefs or interest of society.

The ethical implications of Foucault's epistemology

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Liberals claim that there is no connection between epistemology and ethics. But if nothing is true, everything is permitted.

And liberals tend to espouse idealism, and oppose materialism, in philosophy. Philosophers are consistent: their thoughts express their ideology.

Epistemology, the theory of knowledge, determines ethics. There are only two possible theories of knowledge – materialism and idealism. The materialist, scientific view, is that space-time is not human-dependent. Our thoughts reflect, better or worse, the reality outside us. Against this, idealists claim that there is no reality independent of us.

Nietzsche and Heidegger were both idealists. Nietzsche wrote, "There is no 'reality' for us – nor for you either, my sober friends." And, "facts are precisely what there is not, only interpretations. We cannot establish any fact 'in itself': perhaps it is folly to want to do such a thing." This was to deny the real world. To Nietzsche, language had no contact with reality. This presaged his later insanity when he lost all purchase on reality.

What were Nietzsche's ethics? He attacked reason and promoted barbarism: "One acts perfectly only when one acts instinctively. … Scientific integrity is always ruptured when the thinker begins to

reason. … It could be proved that all conscious thinking would … show a far lower standard of morality than the thinking of the same man when it is directed by his *instincts*."

He wrote that to "see others suffer does one good." He opposed the French Revolution, the 'supreme rights of the majority', its 'levelling', and what he called its slave morality.

Heidegger wrote in *Being and Time* (1927), "idealism affords the only correct possibility for a philosophical problematic." Heidegger opposed materialism so far as to become a Nazi.

Foucault too was part of this idealist tradition. He acknowledged his debts to Nietzsche and Heidegger: "For me Heidegger has always been the essential philosopher … I nevertheless recognize that Nietzsche outweighed him."

Foucault denied the reality of the world. He wanted to "dispense with 'things'", to "substitute for the enigmatic treasure of 'things' anterior to discourse, the regular formation of objects that emerge only in discourse." He wrote, "I dream of the intellectual who destroys evidence and generalities." His *Archaeology of knowledge* was an attack on science, on the idea of objective knowledge. Foucault held that there was no such thing as objective truth: "What I say does not have objective value." He even claimed that knowledge could be lethal: "it may be that mankind will eventually perish from this passion for knowledge."

He linked philosophy to politics, noting that the ‘general framework of biopolitics’ was liberalism. His ethics were barbarous: he wrote of ‘the glory of torture’, of ‘glorious murders’.

Nietzsche, Heidegger and Foucault all thought that by going beyond the real world, beyond evidence, they had gone beyond good and evil. They claimed that their amorality was a superior morality. Actually, all three were beneath, not beyond, evidence, beneath, not beyond, good. They embraced evil.

Objectified Knowledge and Moral Insight in the Field of Bioethics

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Who dares to argue against evidence based medical practices when delivered by physicians, against cost control measures by managers educated in respected institutions, against laws passed by elected politicians? In the name of "science", more and more people are controlled by experts and rules outside and above their own domain of expertise.

How could ethicists in the field of biomedicine survive in such an environment without being deeply influenced in their practice, obliged as they are to using more and more surveys and financial and empirical studies as the main source of reflection?

We will look more carefully at two situations: firstly, a country which pressures its people in research ethics to ensure that the research industry is efficiently served and maintains its competitiveness at the international level; secondly, the situation of ethicists in clinical ethics who are often limited to risk management. To do so we will apply the concept of "disengagement" put forward by Charles Taylor in his book *A Secular Age* 1-to explain the slide towards the impersonal in the field of bioethics; 2-to show that this objectification of knowledge deprives it of normative force for us, thus separating the knowledge component from the practice of virtue; 3-and to warn that "[the] emphasis on objectified expertise over moral insight is the charter for new and more powerful forms of paternalism in our world.", the epistemic considerations being often used to cover ethical considerations about prestige and power.

Defining Practical Relevant Reasons for Deliberative Procedures

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How to fairly distribute healthcare resources is a problem that must be considered and resolved given the health needs of society and our limited resources to meet them. The standard for resource allocation procedures is Daniels and Sabin's theory 'accountability for

reasonableness' (AFR). AFR requires four conditions are met in order for a healthcare allocation procedure to be fair and legitimate: publicity, relevance, appeals and revisions, and enforcement.[1] AFR underpins healthcare priority-setting in several countries including Canada, Norway, Sweden, New Zealand, and the United Kingdom.[2]

However, despite the use of AFR to guide decision-making, there are parts of the procedure that are not well articulated and face objections. How we answer these objections and further define the theory will affect how we apply it with real repercussions for healthcare decision-making. I will focus on the relevance condition rather than the publicity or appeals ones, although there are criticisms of those two. The relevance condition requires that the reasons for a rationing decision must be ones that reasonable and fair-minded people would accept.[3] However, this is a fairly circular definition since 'fair-minded people' are those who agree to cooperate and be reasonable.[4] While an advantage of the relevance condition is that it is procedural and non-substantive, there needs to be a clear delineation of what is and is not a relevant reason in order for AFR to be practicable.

In this paper I will ask and answer the question: in a contemporary society, how do we determine what a relevant reason is and reject our or others' reasons as irrelevant, i.e. how do we justify the claim that a reason cannot be reasonably agreed to? The challenge of this question lies in overriding the traditional assumption that irrelevant reasons are most frequently religious ones that are clearly distinct from 'secular'

reasons since secular reasons may be equally unshared as a form of public reasoning. Daniels and Sabin assume that religious reasons will be unacceptable, but critics of AFR object that utilitarian reasons are no

more acceptable than religious ones.[5] A secondary problem this will raise is whether prioritisations are biased towards those who do not justify their reasons religiously.

I will answer the question with a practicable definition of relevant reasons for AFR that restricts reason-types in a coherent manner. In answering the problem, I will draw on Rawls's concept of public reason and use it to consistently delineate relevant and irrelevant reasons. An important feature of my answer is that it does not rest on empirical claims about what people take to be relevant reasons, but it still allows us to make distinctions that are plausible in contemporary society. A normative definition of relevant reasons that can resolve the problem of the justificatory grounds for relevant reasons will have practical effects on current healthcare decision-making and resource allocation.

[1] Daniels, Norman and James Sabin, "Limits to Health Care: Fair Procedures, Democratic Deliberation, and the

Legitimacy Problem for Insurers," *Philosophy and Public Affairs* 26, no. 4 (1997): 303-350.

[2] Daniels, Norman, "Equity and population health: toward a broader bioethics agenda," *Hastings Center Report* 36, no. 4 (2006): 22-35.

[3] Daniels & Sabin (1997); and Daniels and Sabin, *Setting Limits Fairly* (Oxford: Oxford University Press, 2008).

[4] Daniels & Sabin (2008).

[5] Friedman, Alex, "Beyond Accountability for Reasonableness", *Bioethics* 22, no. 2 (2008): 101-112.

Mitochondrial Transfer: The Bio-political Context of the Public Debate

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Mitochondrial DNA (mtDNA) disorders are commonly inherited diseases that cause immense suffering and even death. New technologies now allow parents who are likely to pass on such a disorder to their child the option of having a genetically related child without an mtDNA disorder. They do this by replacing mitochondria carrying harmful DNA mutations with 'healthy' mitochondria from donated eggs. These novel technologies thus carry tremendous potential benefits. However, they also raise important ethical

challenges related to the unknown risks they may entail for offspring and to the long-term effect of manipulating the human germline.

Recently, a heated public debate has been emerging surrounding these technologies and the coverage of this debate in the media has been extensive. This talk will present the main arguments offered by proponents and opponents of these technologies. It will also present the various portrayals of this technology in the media and offer some reflections regarding how different framings may shape the public debate. It will analyse the implications of using sensationalist terminology such as "three-parent baby" and "genetically modified babies" versus more neutral and scientific terminology such as "mitochondrial transfer" and even favourable terminology such as "mitochondrial replacement therapy". This exploration at the interface of media coverage and public debate will raise some more general issues related to the role bio-politics may play in the introduction of novel – and potentially risky – technologies.

Children as moral agents in time. Decision-making about bone marrow donation to siblings and the ethical significance of children's biographies

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One of the best-established and medically successful forms of live tissue donation is hematopoietic stem cell transplantation. A transplantation of bone marrow or peripheral blood stem cells can be performed between matching siblings. The recipient can be a child who is suffering from an acute form of leukemia, such as ALL or AML. The donor can be a young child from 1 year of age onwards. Some countries allow the conception of matching siblings using preimplantation genetic diagnosis for HLA-markers ("saviour siblings"). Among the many ethical issues that are discussed, some arise in the decision-making procedures. Under which conditions can a child be used as a stem cell donor *ethically*? For obvious reasons a small child cannot be asked for providing a free and informed consent. In clinics, a combination between proxy consent (provided by the parents) and children's assent (according to their age) is the current practice.

We will argue that for a number of reasons the expansion of informed consent to parent's proxy consent (plus the child's assent) is an

insufficient concept to understand the ethical significance of the involvement of a small child as a donor and to support its involvement. A different approach is necessary. This includes both a developmental perspective and seeing the child as a moral agent in time, which will later in life look back to what happened or what had been told. It therefore includes a narrative dimension, which addresses how the subjectivity of the child, his or her self-development and body boundaries, were respected both at the time of the 'donation' and during the time afterwards. The key question then is how the decision about using the child as a donor can meaningfully be integrated into the donor's biography. The talk will flesh out this argument.

Public Perception of Research Ethics in Human Tissue: Some Preliminary Findings from Focus Group Study

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Given the ever-increasing potentiality of human genome medicine, biobanks has trials seeking approval for new drugs. As a result, unless stored human specimen is part of a registered biobank, if the researcher wishes to conduct new research from leftover specimens, researchers must gain re-consent from the participants after informing them the new purpose of the research.

Regulations as such manifest a new balance between the participants and the researchers who use to rely on blanket consents. By imposing the legal requirement of participants' informed consent to specific research purpose, the new law serves as a mediating institution between the biopolitics among the government, researchers and participants and the bioethics involved. Yet, while these regulations empowered participants in their relationship with physician researchers, it creates impasses for the latters that find the tasks of gaining re-consent for secondary usages of left over specimen daunting.

How does the public perceive the legal requirements that were meant to protect them? How can participant protection in secondary usages of human specimen be meaningful to the participants? Issues like these would shed light on how the law should be interpreted or revised.

To answer these questions, we conducted a focus group study of patients with different diseases in the style of public deliberation, and compare their perceptions before and after the discussions. Our study shows that patients have a strong sense of entitlement for their human tissue, hence demands informed consent when their tissues are used for research even when it is delinked. But their attitude changes after being more informed and having discussions, and are willing to rely on institutional settings such as IRB if they are trustworthy. This suggests we should focus more on institutional designs that can

promote accountability rather than the zero sum dilemma of having informed consent or not.

Battle over the conscience clause in Poland

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Poland has one of the most restrictive abortion laws in Europe, both on paper and in practice. Termination of pregnancy is legal, but only in limited circumstances, and even women who meet all requirements prescribed by law, are often denied access to the procedure. Many regulatory, institutional and social factors contribute to this situation. One of them is a so called “conscience clause”, which was introduced to the Polish Code of Medical Ethics in early 1990s, and later to Article 39 of the Act of December 5, 1996 on the Profession of Physician (subsequently renamed the Act on Professions of Physicians and Dentists).

The “conscience clause” allows physicians to refuse to provide medical services that violate their conscience (eg. abortion), unless there is a case of emergency. If the physician wants to make a use of the clause, he is obliged by the law to indicate the patient an effective way of obtaining the denied service from another physician or in

another health care facility. He is also obliged to justify and record the refusal in the patient's medical records.

The "conscience clause" aims at protecting moral integrity of a physician, within the limits compatible with the due respect for patients' rights, in particular right to healthcare. However, many Polish physicians believe that it gives them almost unlimited freedom in deciding what kind of services they are willing to provide to the patients. They often ignore law, which prescribes conditions of using the clause.

The improper use of the "conscience clause" by the Polish physicians, especially in the context of reproductive medicine, has been criticized by many international organizations and institutions, including the UN Human Rights Committee, the UN Committee on Economic, Social and Cultural Rights, the UN Special Rapporteur on the Right to Health, and the European Court of Human Rights. Despite the criticism neither Polish government nor medical community have taken any actions to guarantee every Polish woman and man access to legal and safe reproductive and sexual health services.

In November 2013 the Bioethics Committee at Presidium of the Polish Academy of Sciences issued a position statement on the "conscience clause" in which it reminded ethical and legal rationale behind the clause as well as presented a well-argued interpretation of the existing regulation. The statement initiated a hot debate in media and in medical and bioethics community. Women rights advocates,

liberal bioethicists and politicians have supported the Committee's position. Conservative commentators have argued against it. In December 2013 the National Board of Physicians issued a contra statement to the one published by the Committee. In February 2014 the Team of Bioethics Expects of the Polish Bishops' Conference did the same. The discussion is still on now and getting hotter.

This presentation has two aims: First, to present the background and dynamics of the Polish battle over the "conscience clause". Second, to provide a critical ethico-legal analysis of the clause in the broader context of human rights and the status of medical professions in liberal and democratic societies.

They would simply would not follow – patients´ objection to accept the idea of advance directives

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The idea of advance directives had been discussed for years. It emerged as technical progress had been made for the treatment of life threatening conditions, e.g. emergency medicine, cardiopulmonary resuscitation, continuing life support techniques. Yet, it remained unclear if outcomes had been in the best interest of patients. Hence, the question of foregoing life sustaining treatment arose. To guide

decision making at the end of life in case patients are no longer able to decide for themselves it had been proclaimed to educate persons to make their decisions in advance. As there had been doubt whether medical teams should follow what had been laid down in an advance directive the binding nature of such documents had been regulated in many countries by respective laws. In general the ruling is that advance directives are binding. Yet, after coming into effect the spread of advance directives had not been increased in most countries.

In this paper the reasons why only a minority of persons is fulfilling an advance directive is examined based on recent empirical research of our group. Altogether about 1800 questionnaires had been analyzed. Results of studies that explore acceptance of advance directives before and after a respective law had come into effect in Germany are compared. In the studies the same instrument, a structured questionnaire had been used. In general, only a minority of persons and patients have an advance directive even after the law had been implemented, e.g. only 11% of patients suffering from cancer. A significant portion of interviewees was undecided with respect to particular modalities of treatment at the end of life and revealed apprehensions about potential misuse of ADs. The fear that advance directive will have an unwanted effect on future treatment is underestimated in bioethical discourse. Acceptance of ADs amongst patients remains low. Hence, alternative strategies such as advanced care planning should be implemented in medical practice to improve

care at the end of life. And moreover, research shows that against bioethicists´ theory a majority of patients prefer to rely on their doctors´ decision-making.

Ethical issues in public health surveillance

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Goals of the session:

- To raise awareness for ethical issues in surveillance
- To report on WHO's recent international consultation
- To solicit recommendations from the audience which will feed into current policy-making in this area

Surveillance, often referred to as “the eyes of public health,” is widely recognized as a fundamental public health activity. It often requires physicians, health care institutions, or laboratories to report not only numbers of cases but also the names of those with a disease or condition, both infectious and chronic. Tuberculosis reporting, for example, is a long tradition; diabetes surveillance is new to many industrialized nations. Disease notification has received new emphasis in the WHO’s revised International Health Regulations (2005).

As critical as surveillance is to the practice of public health—enabling officials to map epidemics, treat cases, and target resources—it may also conflict with individual rights claims. Often, given the need to control disease at the population level, it is undertaken without informed consent, one of the most central requirements of research ethics. Likewise, it sometimes creates profound privacy concerns. In some instances, individuals worry about the stigma and discrimination that may result from the disclosure of personal information. In others, they fear the loss of liberty or autonomy if surveillance has the potential to trigger measures like quarantine or mandatory treatment. These kinds of tensions may be magnified in countries where electronic medical records are increasingly used.

Surveillance has also been at the center of controversy over the technical distinction between research, which requires ethical oversight, and public health practice, whose limits are typically a function of law, policy making, and public debate. There are also important issues related to tissue sampling and sharing of specimen and infectious agents (such as virus-sharing).

Remarkably, while there have been some efforts to craft surveillance guidelines for specific diseases, WHO Member States currently lack a comprehensive normative framework and specific guidelines on public health surveillance. WHO has been working with partners to develop guidance on this issue by 2015 and organized a consultation in May 2014. The main findings of this consultation will serve to

highlight the key issues. It will be important to receive feedback from participants in the ESPMH conference, which will directly feed into the further development of WHO guidelines.

Beyond bioethics and biopolitics? Doing privacy ethics in whole Genome sequencing research

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The aim of this paper is to illustrate and critically analyse the political implications and dimensions of acting professionally as a philosopher and ethicist in the field of privacy and data regulations in institutional whole genome sequencing research. In the analysis, I will apply some of the tools and concepts of the critical thinking on biopolitics (following Foucault). I will show that in the field of international genome based research many differentiations, borders and concepts of classical bioethics and biopolitics are blurring – which is quite typical of the postmodern age. In this field of research, the ethics of privacy extends beyond traditional bioethics and its political dimensions beyond classical modern biopolitics. Medical research, e.g. cancer research, is producing an enormous and rapidly increasing amount of genetic data through high throughput sequencing. Researchers seek to bring together the genomic and clinical data of patients of all over the

world in order to have extensive and statistically significant data samples of even rare diseases or pathways. They claim that matching and sharing data in international or global research consortiums and alliances will lead to a better understanding of diseases and might dramatically improve health care.

While this research seems to be very promising for future patients, the data necessary to undertake it stem from actual patients who won't benefit from it but are exposed to risks concerning the confidentiality of their personal data. Even though the data used in international bio bank based research is usually pseudonymized, the genetic data is self- identifying: every one's genetic germ line is unique so that even anonymized research subjects might be re-identified. There are risks of re-identification and abuse of personal and genetic data by third parties such as companies or governments increase. According to Foucault's critical and historical analyses, biopolitics consists in the knowledge and techniques enabling to regulate the life process of a subjected population. Biopolitics or biopower combines the domination of the individual bodies as exercised by modern systems of sovereignty with regulation techniques applied to the mass of people in order to reach statistical population objects.

However, there is no determined population anymore that might be subjected and biopolitically regulated by a local state or power. Within the dynamics of globalization, new forms of global populations emerge: the population of all human beings, or more

specifically, populations whose identity is determined by scientific authorities on the basis of determined biological or statistical features. Also, there are data instead of material bodies and juridical persons. The nudity of the homo sacer is a virtual and informational one. If you, as an ethicist, ask for specific privacy protection measures on the local level, researchers might answer you that there is no local level and that too much privacy would just mean the end for their research. The power structures thus are omnipresent, but not transparent. It is ethically easy to invoke that everybody should take his or her personal responsibilities towards the patients and their data, but it is politically hard to find a personal addressee for this claim.

Of Emerging Life in Law: the European Story

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The notion of life at its margins has had a notable attention already for decades in both academic and public debate. Yet, the recent legal developments and the emerging incommensurability of the two regional legal systems—the European Union and the European Convention on Human Rights—in their response to variegated forms of emerging personhood, have put to the fore once more the question of beginning of life. Does dignity as protected in the Charter of

Fundamental Rights of the European Union belong to non-humans (*Brüstle*) or is destruction of such dignified beings more benevolent when controlling the health of the population (*Costa et Pavan c. Italie*)?

Reading these developments through the texts of the Italian biopoliticians, most notably Agamben and Esposito, and their concepts of life and personhood, it is explored whether the diverging legal conceptions over the beginning of life are commensurate on a more profound, culturally manifested level. The insights gained through such deconstruction of the law are instilled back to the system of law. Returning the more embryotic notions of life to the realm of law, I seek to explore how early life is governed by the European legal order. By using the notions of pastoral duty, as developed in the oeuvre of Foucault and Rose, the role of Courts in dictating the exclusion and inclusion of life is explored. It is argued that through their actions, the Courts create a proprietary (legal) definition for the European Life.

To better understand the significance of the border between legal personhood and non-personhood, the notion of subject as developed in early Badiou, is employed to conceptualise the violent nature of subjectivization. Much like the illegal immigrants taken as an example by Badiou in his *Theory of the Subject*, the non-personhood of emerging life is that what limits the whole of personhood. Through a scientific gaze cast at gamete, blastocyst, or embryo we are able to

discern that which is liminal. Unlike death, where the border is past our technological gaze, the birth as a gradual process is tangible and discernable. For law this poses an insurmountable problem, for drawing line means totalitarianism and refusing to draw it signals indeterminacy. I argue that the proprietary European (legal) life, emerging through indeterminate legal rapprochement, affects not only who and what we consider a legal person, but also how we conduct our policy towards those separated from us by more notable (geographical) borders.

Communication of Incidental Findings to Research Participants: Practices and Ethical Concerns

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As genetic diagnostics develops, medical research faces a growing number of occurrences of incidental findings: unexpected information that is out of the focus of the research project, but relevant for participant's health. In such situation, the research team is caught between two different sets of guiding principles, that of beneficence and avoidance of harm relevant in clinical care, and that of creation of new knowledge and public health values in research. The paper studies the practices of communicating such incidental findings to

research participants. Based on semi-structured interviews with members of research teams (geneticists and doctors) it discusses how the "risk thresholds" are determined when informing becomes necessary; what is the practice of dealing with research participants who refuse to be informed at the outset of the study; how well are research and procedural guidelines adapted for such incidents (inclusion in informed consent). Special focus is on the ethical and practical considerations of the members of the research team behind the decisions to inform the research participants. The initial findings suggest that clear guidelines for reporting incidental findings are lacking and the decision when and how to communicate such findings rests primarily with the research doctor. The factors influencing the decision include the nature of the illness (curability, heritability) and the psychological state of the research participant. The doctors are guided primarily by clinical ethics and in certain cases are ready to go to great lengths to talk round people who have refused to be informed.

Blood donors and healthcare workers' perspectives on notification process of permanent deferral: preliminary results

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*Background***:** Donors are voluntary and healthy but may be confronted with deferral and labeled as carriers of an unexpected transmissible disease. After a while, and even though the target condition has been discarded, blood banks will keep permanently the level of "permanent deferral", preventing them any donation (tissues and organs) for life.
*Objective***:** To examine the permanent deferral notification process from the healthcare workers' perspective, and to explore the permanent deferral experience from the donors' perspective.
*Methods***:** Using grounded theory methods; a qualitative research study was conducted with eight healthcare workers, and eight donors who received notice of permanent deferral in three deferral categories: VIH, hepatitis C virus and syphilis. The study took place at the biggest Mexican blood bank and was approved by the research ethics committee.
*Results***:** The healthcare workers responsible for notification are more concerned about following norms and regulations of the blood bank than about the wellbeing of the donors. The permanently deferred donors described a variety of negative emotional and behavioral

responses including confusion, fear, anger, stigmatization, labeling, and loss of hope.

Conclusion: This is the first study to use qualitative research to explore the attitudes of healthcare workers and the experience of permanent deferral blood donor. And it is part of a larger, current ongoing, research on this specific context.

Assessing the quality of published research

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Background*:* Assessing quality of research is difficult in our very sub-specialized fields but a variety of object measures are used in an attempt to do so. One of the most commonly cited is journal impact factor (JIF), based on the assumption that important research is more likely found in journals that are frequently cited. Alternative modes of assessing research need study.

Methods: A literature review was performed using all PubMed sources for "journal impact factor" (JIF) reported since the widespread use of electronic publication of medical findings. Cited articles were divided into those for general and those for specialty readerships with use of only the former. References were used to establish other quantitative

measures for assessing journal publications. Secondary searches for these terms were undertaken.

Findings: Besides JIF, other less often-used measures used to assess quality include a reading index, an immediacy index, the citation half-life, the PageRank index, an eigenfactor, and SCImago Journal Rank. Essential differences among the measures include the time interval examined (two years prior to index for JIF, one year for immediacy index, five years for eigenfactor), differences in what is included in the denominator (for example, should letters, news articles, errata, and ancillary comments which are not used for JIF, be included) or numerator (for eigenfactor, citations in the journal under study are not included), should searches be limited to electronic sources (a convenient mode of acquiring data and used exclusively for reading index and PageRank) and should iterative algorithms be included which target the perceived prestige of a given journal (the methods used for SCImago and PageRank).

Conclusion: Quality is an elusive term in assessing research and indirectly journal quality. Measures of journal quality are increasing using electronic resources. The presence of measures that assess citation half-life and measures that use only the past 1-2 years for calculations suggest that newness of data and findings are disproportionately given weight in such indices. Future assessments against quality could be measures that assess publications resulting in major awards (Lasker, Nobel, Institute of Medicine membership of

authors) or in the use of the expert opinions of senior clinicians or scientists. In the end, each field needs to assess its own measures of quality and indices should as JIF or its related measures can only be at best approximates in assessing quality of research.

Subjective Esthetics vs Objective Decisions

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Breast augmentation is generally performed on request by women desiring to enhance nature’s endowments. This elective procedure is not considered essential for promoting or maintaining health but is defined as a "cosmetic procedure" per-se. In Israel, the market for breast implants is diverse and uncontrolled. Mostly, these procedures are performed in private clinics. Even though women sign a consent form, they are usually unaware of the kind of implant installed and possible complications.

In recent years, reports have been published, firstly regarding the quality of the implants and later on, their leakage. These incidents were perceived as a threat to women's health. In 2012, turmoil erupted in Israel regarding the (PIP) implants. The Israeli Ministry of Health (MoH) asked the population with PIP implants to contact the MoH, giving details of the procedure conducted. The MoH also announced

that the surgical extraction of the implants will be financed by public funding. This led to controversy among the women affected, the MoH and the general public raising doubts regarding the moral justification of the MoH decision:

1. With limited public resources available is it right/just/fair/correct/reasonable to allocate resources for treatments that are not considered necessary instead of allocating them for "life-saving" treatments?
2. What is the moral responsibility of the government for these personal cosmetic decisions?
3. What are the boundaries of personal/public responsibility?

Ethical approaches: deontology, utilitarianism and moral luck may assist in enlightening the rights and duties of the patient and the MoH.

The morality of deportation of sick illegal immigrants

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In recent decades considerable efforts have been made by many migrant workers from third world countries, to immigrate to developed countries in order to improve their wages and quality of life. This is often done in contravention of immigration laws of the destination country, especially when seeking a better life into it, such

as infiltration made to the United States from the Mexican border. Developed countries are trying to struggle with this issue in various ways.

As in other developed countries, the phenomenon of migrant workers also exists in Israel. Illegal immigration from Africa to Israel is relatively easy due to Israel's land border with Egypt.

Regarding sick illegal immigrants, the possibility of access to health care institutions in most European countries is limited to emergency situations only. According to a new report by the Center for Social Justice at Seton Hall University School of Law and New York Lawyers for the Public Interest, as United States hospitals deal with the constant need to cut expensive costs of care, some are choosing "unlawful" deportations of illegal patients in order to save money.

Utilitarianism refers to the concept which states that ‘the ends justify the means’ i.e. the value of an action is determined by its contribution to overall utility and happiness while minimizing the suffering. This doctrine says that actions are morally correct, as they tend to increase happiness. Thus, this philosophy completely depends on consequentiality and is considered as a selfish approach as it doesn’t take into account any kind of suffering which the society may face due to a particular action plan. In contrast, deontology is based on fairness and social justice. The moral value of the action lies in the act itself. There are things that are worth doing and there are things that we will do and no matter what will be the outcome.

With limited public resources available in the Israeli Health Care System, is it reasonable to allocate resources in taking care of people who are not citizens, who enter the country in an illegal way and are not contributing to the country?

In one side, it is argued that a country has a moral obligation to provide health care to all those within its borders needing such assistance. On the other, it is argued with equal force, that those illegally present in this country should not be entitled to take advantage of public benefits.

The presentation will include the arguments of the questions arise, the ethical approaches involved and conclusions regarding health coverage for illegal immigrants.

Aristotelian Nicomachean ethics from the perspective of teacher of care ethics

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Pluralist society needs ethics, which respects unique individuality of ethical agents. Author of the paper would like to provoke discussion on some issues in Aristotelian ethics which are often abandoned but which could be helpful from the perspective of care ethics.

Aristotle in his Nicomachean Ethics points out that we can describe ethics only approximately. Respect for this could open the room for individualised strategies and actions.

Care for others need not be a sacrifice; it could be the component of happy life. Eudaimonia is an old Aristotelian concept, but the perspective of eudaimonia could help to better understand Tugendhat's thesis that ethics is rooted in the freedom of will, it is in accordance with Fromm's concept of productive personality and Erikson's concept of integrity. The Czech philosopher Jan Patocka emphasised importance of the sense of human existence. The sense could be derived only from understanding human life as a whole. Eudaimonia encompass all these aspects.

Edmund Pelegrino consider Aristotelian concept of strength as a mean between two extremes as the weakest point of Aristotelian ethics. On the contrary, this concept opens the space for individualised moral behaviour in the unique situation of acting human beings. Aristotelian mean is not arithmetic diameter. It allows everybody to find his own position between two borders given by definition of extremes.

Incidentalome – debating the feedback from genetic research

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"Genes Now Tell Doctors Secrets They Can't Utter" was the dramatic title of the New York Times article from August 2012 that described the problem of incidental findings in genetic research. Indeed, the issue of whether or not to disclose significant genetic information to donors or participants of research that generally do not expect it is a much-discussed topic in medical ethics and genetic journals and has now spilled over into general media.

The biobanks that had promised feedback to their participants have by now managed to collect some information that they plan to return. At the same time in countries where research biobanks did not plan giving feedback, prominent stakeholders in the field have started to question the ethical justifiability of such a stance. The right to know or not to know discussion in relation to biobank research is now almost entirely dominated by the so-called "incidentalome" (Kohane et al 2006) debate. Incidental findings are a well-known phenomenon in clinical care where, for example, a radiologist might find something unexpected from an image in addition to the information she was looking for. Genetic research that is often based on biobank collections, is now similarly faced with such findings when researchers stumble upon DNA information that, while not the aim of

research itself, might be potentially very relevant to the donors. But while it might have been relatively straightforward for the radiologist to contact the patient or patient's physician regarding incidental finds, the matter is much more complicated for researchers far removed (both institutionally and geographically) from the biological owners of the mostly anonymised samples.

The situation raises fundamental moral issues and challenges the traditional ethical frameworks that guided and divided the fields of clinical medicine and research. Traditionally the ethical principles of clinical medicine have centered on the importance of respecting the autonomy of the patient, treating her with beneficence, non-maleficence and justice. Researchers, on the other hand, have traditionally been seen as having duties not towards specific persons but towards science, truth and future generations in a more general sense. With the emergence of personalized medicine and in the context of potential feedback, the borderline between research and health care is blurred.

The presentation aims to clarify some fundamental distinctions in the incidentalome debate, taking into account the recent more normative propositions (Bovenberg et al 2009, Berg et al 2013, Bredenoord et al 2011, Wolf et al 2013, Anastasova et al 2013) as well as investigating its not-so-well-justified premises (e.g. that people will indeed make use of the disclosed information).

The theoretical discussion of the arguments for and against feedback from genetic research will be illustrated through a qualitative study of Estonian doctors and their communication strategies regarding incidental findings from genetic research.

Gayness from biology to bioethics

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The human sociobiological, adaptionist model of homosexuality – biology and psychology: or how can we give a description of the topic in humanities and sciences simultaneously?

For a long time, unfortunately, even homosexuals regarded themselves to be the dead-end of biology. Research and theoretical systems of contemporary evolution science of 1978, 1995 and 2000 have come to the conclusion that the above view is mistaken and not true.

In as early as 1978, Edward Wilson, father of human sociobiology, suggested that homosexuals make use of their energies (possibly saved in excess owing to the lack of reproduction) in taking care of their collateral relatives as it has been shown by cultural anthropology, in traditional tribal communities, e.g. in Haiti. In 1995, it was scientifically justified that, compared to heterosexual men,

homosexuals had a higher level of empathy in a large population (Salais and Fischer, 1995). Cohesion within groups in homosexual populations was also found to be much stronger by Kirkpatrick and Muscarella in 2000 and 2001, respectively. Genetic and statistical research by Camperio-Ciani, 1992 in a large population has revealed that a mother delivering a gay child is more fertile on average than her counterparts solely giving birth to heterosexual babies. (Of course, "researchability" has been influenced by the spread of modern contraceptive methods.) A theory has been based on the above statistic: Xq28, which is part of the gene located on the X-chromosome, and responsible for the development of homosexuality among others (Dean Hamer, 1993), re-reproduces its own "lost" reproductive activity. That is, homosexuals are not against reproduction, on the contrary, they form a biological community together with them. That is how a hypothesis (Robert Trevis, 1994) has been confirmed: if nature produces a genetic group like that, it should have a biological-communal function.

Influenced by the results of the above research, the latest and most dynamically developing branch of psychology claims that, in a complex society, heterosexuals are responsible for reproduction, the growth of the community in size and quality, but the "homosexual alliance" ensures the unity and social coherence of the community. Thus heterosexual reproduction and homosexual alliance together form a natural and healthy society.

From Choice to Creation: Legislating for Mitochondrial Transfer in Reproductive Technology to Eradicate Inherited Disease and Address Infertility

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In 2001, US researchers announced 'the first case of germline modification'. They had effected ooplasmic transfer to enable women with impaired fertility to achieve pregnancy. In 2002, the FDA announced that at least 24 births attributed to ooplasmic transfer had been reported by fertility clinics. It expressed concern about this technology, its potential to alter the human germline, the risks associated with mitochondrial heteroplasmy, the high incidence of abnormality reported, the paucity of animal trials and other pre-clinical data and said it was not clear what defect was being corrected by this technology. The FDA instructed clinics to cease offering this procedure. In 2009, researchers in Oregon created ova with donor mitochondria that developed into healthy rhesus monkeys. In October 2012, the same research team reported the creation of human embryos in which all the mitochondria were donated. This new mitochondrial transfer technology has the potential to eradicate serious diseases inherited through the maternal line, e.g. muscular dystrophy, and to benefit infertility treatment in older women. Following public consultation, the UK government has announced that it will draft

legislation to permit mitochondrial transfer in 2014. It will be the first country to allow this technology, notwithstanding international prohibitions on alteration of the human germline. The US held scientific hearings open to the public on 25 and 26 February 2014, and is reassessing its position regarding this technology. This paper reviews the scientific evidence. Then, drawing on the report of the Nuffield Council on Bioethics and considering Constitutional, Union and international law, including recent decisions of the Irish courts and the CJEU, this paper critically examines the ethical and legal arguments for and against this 'disruptive' technology, including the impact of philosophical concepts such as dignity and morality on the advancements in reproductive medicine.

Health and policy: Assisted reproduction policies in Israel, a retrospective analysis in two major IVF clinics[i]

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The objective of this study was to analyze whether the results and effectiveness of the open ended treatment with IVF in Israel justifies the policy of limitless non-donor IVF rounds. The research sample included 535 patients from two IVF clinics located in two large

regional hospitals in Israel. The files of these patients were reviewed; data was extracted into a questionnaire, transferred into digital files and analyzed with SPSS. One cohort of patients included 210 women who begun with IVF treatment in 2000; a second cohort included 325 women who were in treatment during 2010.

In the 2000-cohort the rate of success with IVF was 54%. The rate of success fell as the number of cycles increased; age at the beginning of the treatment was influential. The rate of success with IVF in 2010 was *lower* than in 2000; this gap appeared already in the first three cycles with IVF in women of *similar age* at the beginning of treatment. We conclude that the policy of limitless IVF cycles in Israel is ineffective and unjustified; and, suggest that the lower rate success in 2010 when compared with 2000 should be further investigated.

[i] This research was funded by the Gertner Institute of Health Policy in Israel.

Prenatal life — classifying and governing

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The paper examines the theme of the prenatal life as the specific part of contemporary forms of biopolitics, biopower (Foucault, Arendt,

Heller). This is analysed in the particular example relating to the current Czech reproductive medicine. From the standpoint of critical social theory, defining, testing and governing the prenatal life are typically biopolitical not only for its use of terminological purification, and the desire to decision of when a human being is an object of biology and when an subject with rights. Prenatal care is also an example of the biopolitical management of the population and the technology of specific treatment, definition, or shaping of the category of *life* itself (Foucault, Agamben, Lemke). Although current biomedicine offers sophisticated classification of prenatal life, the gradual development from the fertilized egg, stem cells, zygotes, embryo, fetus, the individual medical subdisciplines do not offer a clear borderline for when life begins as a being, as a person (Gilbert). Taking advantage in critical theory and works of Giorgio Agamben, Hannah Arendt and Michel Foucault the paper is inspired with the concept of life as a duality of *zoe* and *bios*. Agamben and Foucault point out that today *zoe* is coming to the center of politics and management of the population. Foucault also develops the ideas of Hannah Arendt, who in her text *The Human Condition* describes the way in which *homo laborans* is constituted, and how biological life as such gets closer and closer to the very center of the political scene in the modern era. Michel Foucault connects with creation, description, control of the living person, population, society a certain type of power that he calls biopower or biopolitics. At the present time thanks

to the technology of prenatal care, the debate over the definition of life is expanding to unborn life or to the molecular stage. The idea of life was molecularized, and postulates a vulnerable Subject, who is thrown into an unpredictable molecular world characterized by constant change, flow, and "the constant presence of risk" (Brown). The paper analyses the ART treatment, particularly prenatal testing and using of biotechnologies, as example of specific biopolitical rationality/ governmentality (Rose, Rabinow), which have emerged in current reproductive medicine in the last years. The category of "social good" with reference to the issues of prenatal testing, is part of a practice that is intended to help avoiding birth defects or enabling the enhancement of embryos. However, in the ambivalent janus-faced spirit of the modernistic demand of expert knowledge for definition, recording, representation and administration, new types of risk and bioethical questions are generated (Rapp).

An ethnographical and narrative analysis of Czech genomics and reproductive medicine field concerning the popular/scientific representations of human genomics are concerned. Particularly interviews with geneticists, embryologists, IVF process actors as well are analysed.

Genomic research and personalized medicine: - Has the time come for dynamic consents, participatory research and return of results?

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Population based biobanks and large scale genomic research made "informed consent" a hot topic again in today's research ethics. Specific consents were abandoned and broad consents were embraced by the research community. But critical voices claimed that people were ignorant about the transformative potential of this type of research, that their passive participation was a democratic problem and finally that they were entitled to receive individual results from genomic research as a token of respect and reciprocity. A new vision – consisting of dynamic consents, participatory research and return of results – aims at "solving" the shortcoming of older consent-models and return of results models. In addition it proposes a fundamentally new relation between researchers and research participants. Has the time come for such a model, or are there important ethical objections to this solution?

Moral enhancement and moral authenticity of the self

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The paper addresses the issue of moral enhancement of human beings by biomedical technologies. It analyzes the idea of cognitive enhancement aimed at improvement of moral dispositions. The idea rests upon the naturalistic assumption that the core moral dispositions have a merely biological basis. The proponents of the idea claim that enhancement technologies are just new means to achieve the same old goal as moral education or socialization and are to be treated on par with these methods. I shall challenge these statements by invoking moral-identity-related objections to moral enhancement, namely two arguments discussed by MacIntyre and Taylor: (1) the argument form freedom and self-creation (deciding who one can become); and (2) the argument from authenticity (being true to oneself). To realize this aim, I shall investigate the concept of moral identity of the self and its significance for understanding moral agency. My thesis is that advocates of moral enhancement fail to identify specifically moral capacities because of their reductionist view of morality. Furthermore, the claim that cognitive enhancement is equivalent to moral self-improvement is based on a reductionist view of a moral agent and thus seems to be deeply misleading.

In Defense of Suicide Tourism (ST)

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Recent reports from across the world involve stories of citizens embarking on trips mainly to Switzerland and Mexico to be assisted in their suicide by some other person/s. In Switzerland, for example, once contacted, a Swiss organisation named *Dignitas* provides background information and examines whether there are other ways of tackling or minimizing the suicidal person's suffering, including through access to palliative care. However, when a person's wish to die is strong and firm, *Dignitas* may locate a Swiss doctor who will issue the lethal barbiturate prescription following a screening process and some legal examination.

From legal and ethical perspectives there are few alternatives for jurisdictions whose citizens are embarking on assisted suicide tourism. These include restricting particular benefits and services (Euthanasia) to residents and/or preventing residents from leaving to take up options available elsewhere; providing a unified and harmonized moral stance with regard to ST; or permitting ST under the assumption that ST can be justified by an appeal to the principle of interstate moral pluralism. Yet, the choice between such alternatives derives from the moral justifications of the practice of suicide tourism that in themselves are linked to the symbolic and emotional meanings

that death carries in each or every society. The article will analyze and discuss these latter justifications and provide a prima facie argument in support of the practice of ST.

From bio-politics to political bioethics

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The biopolitical theory, coined by Rudolf Kjellén almost 100 years ago, has a descriptive, sometimes reductionist and discriminative character and doesn't fit with contemporary survival imperatives of humankind, which are facing critical global problems. Contemporary global crisis is much more dependent of moral revival of humanity than previous global hardships.

Moral component of the the theory of bio-politics has only a peripheral role, which is willfully neglected when the narrow corporatist interests of elites are protected using biopolitical methods and aproaches, at the expense of interests of majority of population.

In this context, become necessary to establish, substantiate and promote a new branch of bioethical science in the way to offer a better chance for humankind to overpass global crises – political bioethics, as a new innovative bioethical dimension and a tool for implementing the theory and practice of humanhood survival.

If the Van Rensselaer Potter's concept of global bioethics is dominated by the question of global crisis and of humankind survival, political bioethics is focused on necessity of assuring of immediate or strategic and long-term safety using political and public leverages. The concept of security, at individual and global scale, represents basic theoretical pillar of political bioethics, created to enrich methodologically the applicative potential of current human society to edify sustainable institutes and organizations for an efficient surpass of contemporary global elbow.

There are several branches in bioethical research as social, clinical or global bioethics. Among them, political bioethics is focused on widest strategic forecast of impact of different political aspects and consequences of relations between society and nature, involving alive beings, life or biosphere. A permanent exchange of information and know-how between political bioethics and other bioethical branches is crucial for strengthening the long-term social bioethical impact.

Political bioethics, as a practical domain, deals with pressure of policymakers on bioethical institutions and on bioethical social consciousness, with the influence of bioethical organizations, scientific and professional communities on social-political decisions. As a theoretical discipline, political bioethics have to be grounded on comprehensive theories, concepts, and categories related to political life in conditions of multidimensional global crises and imminent necessity of revising moral norms and principles, converging to

preservation of rights and safety of alive beings and biological environment's welfare.

In conclusion, comparing with bio-politics, political bioethics includes intrinsically the moral aspect, moreover, the ethical factor leads in the discourse specific to political bioethics, as well as in the scale of resources destined for establishing and promoting fundamental principles of safety inter-human and inter-civilization relations for future sustainability of biosphere.

Bioethisation is a new specificity of contemporary society in the Age of global danger and a natural mechanism of self-defense of threatened human communities. This crucial concept for political bioethics touches equally the political life at national and international levels.

Bio-moralization of political life, decision-making or social-political behavior, habits and traditions, concerns subordination of political will and institutions, social strategies and policies to highly important bioethical global imperatives and goals, related to sustainable survival of mankind.

Personalized medicine and trust

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In the vision of personalized medicine data from various technological sources are combined in order to tailor diagnostics, treatment and prevention to the need of the individual patient/person. Personal genomic and biochemical profiles, results from ultrasound, CT and MRI, and continuous retrieved data on e.g. various physiological parameters are gathered and combined with knowledge about the intertwined effects of genetics, lifestyle and environment. Personalized medicine seeks to empower the individual by giving access to both more precise predictions based on these data and to tools enabling individuals to take more control over health related matters. However, the other side of this coin is increased dependency on technology, a gradual shift in responsibility from health services to the individual, and an increased regimen of surveillance and control. This creates challenges for trust, understood as the act of leaving yourself vulnerable to someone else's actions.

Traditionally medical treatment has been an asymmetrical relationship involving a vulnerable patient trusting the doctor's benevolence and competence. The growing significance of patient autonomy and user participation have altered this picture in later years supported by several important technological changes, reducing asymmetry and

altering the kind of trust involved in the doctor- patient relationship. If the promises of personalized medicine are fulfilled one question is how this will affect trust.

In personalized medicine, we will get a complex picture of shared responsibilities between people, technology and its operators and healthcare workers. Although the individual is presumably taking increasing control over own health, and deciding whom to consult, the complexity of the information and relevant technologies required can simultaneously undermine this control and autonomy. She will need help to interpret complex information, to determine the particularities of the prevention or intervention, and to ensure that the technology works. We will here explore this tension and argue that despite the intention in personalized medicine to empower the patient, the mass and complexities of the information and choices involved, makes the patient dependent in another manner leaving trust essential and increasingly important for the future patient.

The Role of Expertise in the Medicalization of Risk

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In November of 2013 a task force of the American College of Cardiology and the American Heart Association released a new set of

guidelines for the treatment of blood cholesterol to reduce atherosclerotic cardiovascular risk. The new recommended method of calculating risk immediately caused controversy. Some argued that the guidelines were an improvement and presented a more rational approach to prescribing statin drugs in the name of public health; others saw the guidelines as little more than an attempt of the medical profession to increase social control or, more cynically, to boost the sale of drugs.

This paper examines the role of the expert panel in the medicalization of risk, focusing on blood cholesterol as a risk factor for heart disease and the perceived need for drug therapy to lower the risk. The role involves two aspects, one epistemological and one ethical. Experts study disease and assess the degree of various risk factors for disease. They also make recommendations about how those risk factors should be treated to prevent disease. What often goes unnoticed by the lay public and even by the experts themselves is the mutual influence of these two aspects. Fact and value are not cleanly separable.

In the epistemological realm, experts are charged with interpreting the myriad data that go into formulating facts about risk for disease. These facts are based on the hegemony of numbers. As Ian Hacking has shown, we have come to believe that statistical patterns are explanatory in themselves, as we have sought to bring about the "taming of chance." In this particular case, the chance is that risk will transform into overt symptomatic disease. In the taming process,

however, we come to see risk factors as a new class of diseases: diseases without symptoms. We will examine how values are incorporated into what masquerade as objective numerical assessments in this process.

In the ethical realm, we ought to consider Foucault's observation that knowledge is power. When experts, presumed to be knowledgeable, begin to present risks as diseases, it become easy to conclude that they ought to be treated. This clearly involves a moral dimension, but when such recommendations are presented as factual it is easy to miss it. We will explore the nature of expertise, how expert and lay interpretation of facts may differ, and how systematic biases in the interpretation process may go unnoticed. Finally, we will look at the historical connection between the diagnosis of risk and the development of pharmaceuticals for risk reduction, and explore the ways in which this association has influenced the medicalization of risk.

Disciplining health checks as tools for self care

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A key feature of prevention of heart disease are health checks: tests on cholesterol, sugar and blood pressure. These checks often include an

assessment of lifestyle risk factors such as obesity, smoking and a sedentary lifestyle. Health checks assess an individual's current health and predict his chance of developing illness in the future. In case of an unfavourable outcome, participants are advised to change their lifestyle. In addition or alternatively, medicines such as statines or beta blockers are prescribed.

One way to describe this situation is to say health checks control or restrain people in their way of living. Seen from a different perspective however, the opportunity to do a health check can be seen as a prompt, a tool to (finally) take steps in improving one's lifestyle, to take better care of oneself.

Foucault's concepts of disciplining and care of the self fit this apparent contradiction perfectly. 'Being disciplined' and 'using healthchecks as a tool for self care' may have the same result (improved lifestyle) by the same mechanism (adjusting norms), but they are perceived and evaluated differently. It seems something different to consciously or unconsciously internalize the norms of public health than to actively use those norms to (re)create yourself.

In my presentation I will discuss differences and similarities between being disciplined, disciplining yourself, and self-care, using Foucault's work on the genealogy of ethics and care of the self (Foucault 1975, 1976, 1984, 1997). I will demonstrate its relevance with examples from empirical studies. Research from health science, psychology and ethics shows that people have different motivations

for doing health checks and evaluate them differently. Their evaluation seems dependent on whether they feel disciplined, or see the check as a tool.

The question that remains to be answered is how to evaluate these different evaluations ethically. Perhaps being disciplined isn't (and isn't always evaluated as) something 'negative'. I will discuss those evaluative questions, as well as implications for policy.

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The Ethics of Global Health Research in Developing Countries and Exploring the Importance of an Islamic Perspective – I: Literature and Guideline Review

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The field of global health research ethics faces the continuing challenge of its application within ethnographically diverse settings. Bioethics has increasingly developed a global consciousness yet universal principles to successfully guide ethical decision-making irrespective of cultural or religious contexts are not available and may never be established. Despite the variety of work that has been accomplished thus far, many researchers fail to take into consideration the pertinence of religious pluralism, cultural differences and moral diversity, which pervades in different societies. It is therefore necessary to assess existing research protocols to establish whether they allow for the necessary cultural diversity and therefore enhance applicability. Bioethical principles, from which research is conducted within a particular setting, should ideally be derived from the moral traditions of the local cultures and religions.

Islam forms the second largest religious affiliation across the world and very little study has been done to explore its role in the context of research ethics. Currently there are 1.57 billion Muslims across the globe accounting for just under a quarter of the world's population.

The majority of Muslims live in the developing world and therefore can form a significant cohort for research as well as those who carry out the research. Islam has generally encouraged the use of science, medicine and biotechnology as solutions to human suffering and as such it would be useful to assess its influence on local (regional and national) ethical decision-making.

This paper reviews the literature, regional and national guidelines assessing the underlying normative principles that govern and inform local ethical decision making, within the Muslim world, and compares these with global ethical principles. This piece of research is an analysis of the current research protocols submitted within the OIC (Organisation of Islamic Cooperation) and focuses on establishing the role, if any, that the Islamic tradition plays within the local and international discourse on research ethics, in informing the ethical decision-making. Themes that are analysed include the complexity of the consent process involving married and single Muslim women, the consent of minors as well as global pandemics such as HIV and scholarly deliberations surrounding emerging medical technologies within genetics and reproduction.

Phenomenology and bioethics: methods and concepts to be considered

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What does it mean to do "phenomenological bioethics"? In this presentation I am towards clarifying and specifying what kind of method phenomenology represents when applied to bioethical questions. Phenomenology is, indeed, not only and primarily a method to be used in qualitative studies, but a form of philosophy and research tradition within the humanities which has spread to many disciplines and fields, recently also medicine and nursing. It has, however, so far, been strangely absent in bioethics.

Phenomenology as a method in bioethics could be used to underline the importance of giving adequate and detailed descriptions of medical ethical dilemmas from the perspective of all involved persons – patients as well as professionals. How ethical principles are to be applied in understanding and potentially solving ethical dilemmas to a large extent depends on the descriptions given of the dilemmas in question and the norms that are implicitly present in giving these descriptions. In this way phenomenology would underline the importance of thick narratives as concerns applied ethics.

However, phenomenology could also, as I will try to give some hints about in the presentation, be used to criticize and develop the implicit

philosophical anthropology present in the use of concepts such as autonomy, suffering and justice in contemporary mainstream bioethics. A phenomenological focus would emphasize the way a person is always dependent upon her embodiment and the social ties to other persons and, also, the norms that are present in cultural ideals of the good and normal life.

Inconsistent Biopolicy of Embryonic Stem Cell Research in Slovakia

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Slovakia, together with Poland and Lithuania, is listed among EU Member States, which prohibit research on human embryonic stem cells (hESC). At the EU level Slovakia belongs to a group of countries, which requested a universal ban on European funding of hESC research within the EU Framework Programme 6, 7 and Horizon 2020 because, according to the Slovak government, this research contravenes the country´s legislation. However, Slovakia as well as Poland and Lithuania, have no specific hESC legislation and their restrictive biopolicies are inferred from other laws. I argue, first, that research at least on imported lines of hESC is not prohibited according to Slovak legislation and second, that prohibition of hESC

procurement from embryos could be based on misconstruction. A ban on the hESC research refers to the Health Care Law No.576 of the year 2004 and Slovak Penal Code No. 300 of the year 2005. Both laws prohibit research on human embryos and foetuses; however, they do not distinguishing between *in vitro* and *in utero* embryos (there is no *in vitro* fertilization law in Slovakia). The Health Care Law straightforwardly places embryos and foetuses among other persons (soldiers, imprisoned and mentally ill persons, foreigners) on which researchers are not permitted to perform biomedical research. Biomedical research is defined at the same law as "every research activity, which can influence physical or mental health of a person taking part in this research (hereinafter 'research participant')." However, embryos and foetuses are not recognized in Slovak legislation to be persons, as it was confirmed in 2007 by The Constitutional Court decision in case of liberal Slovak abortion law. In comparison, Polish biopolicy of hESC research is also full of inconsistencies (despite the existence of Polish anti-abortion law) from which may follow that classification of Poland as a country where embryo research is prohibited is incorrect (Kulawik 2009, 2011). Non-transparency, a lack of deliberative processes like citizen and expert consultations during formation of hESC biopolicy translated into inconsistent public policy on stem cell research in Slovakia.

Ethical challenges in end-of-life care. Decisions about nutrition and hydration

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We live in a time where the prevailing order for doctors is to prolong and maintain life at all costs, and where death is deemed as a "defeat of life." Although it occurred previously, increasingly ethicists and doctors talk about institutionalized dying, and the struggle with death is often outsourced to institutions and hospitals where one often dies alone in the presence of life-prolonging technologies, rather than in the presence of another human being. According to Elisabeth Kübler-Ross, one of the most important factors in our inability to cope with death is that “death itself is now in many ways more frightening as before, much more lonelier, mechanical, and sometimes it is even more difficult to technically determine the right moment of death."
The first part of this study presents the background, ethical aspects, and arguments for finding appropriate ways to take care of the dying, and in dealing with ethical dilemmas that may occur in palliative care. One of the most common ethical dilemmas is concerned with issues like artificial nutrition and hydration, pain-relief (i.e. the use of opiates), chemotherapy, experimental treatments, ventilation, and the resuscitation of a patient. The second part of this study analyzes ethical dilemmas concerning the artificial nutrition and hydration of

patients in a persistent vegetative state (PVS), which constitutes one of the most complex ethical issues in palliative care.

There are different viewpoints among ethicists and doctors as to whether or not artificial nutrition and hydration is a medical intervention, and whether the denial or the withholding of artificial nutrition and hydration is a similar decision to allowing a patient to die. Proponents of artificial nutrition and hydration insist that a person in a persistent vegetative state deserve ordinary medical care. There are other bioethicists who consider artificial nutrition and hydration as medical intervention, and not as an ordinary care. According to the Catholic Church, there should be always an assumption in favour of providing nutrition and hydration to all patients, even if medically assisted, as long as this is of sufficient benefit to outweigh the burdens involved. Water, even when administered artificially, cannot be considered a medical procedure because without it, a patient will die not because of his/her illness, but because of dehydration. It is therefore necessary to ask the following question: Does the provision of nutrition and hydration benefit or burden the patient? Does the principle of proportionality address this kind of ethical dilemma, similar to those cases involving dialysis? How should one proceed in cases involving patients who refuse such ordinary care? Is the administration of artificial nutrition and hydration only a mechanical prolongation of life? How should one approach the families of these patients, who often ask for extraordinary care for these patients? Why

do we not let people whose deaths are inevitable just die? This study does not claim to find all of the answers to these ethical issues, but rather it offers ethical criteria and solutions to these dilemmas based on available resources and materials.

Bioethics as politics

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Bioethics has never been far removed from politics or political agendas. For instance, many of the early contributor's argued fiercely for the rights of women - or the rights of unborn babies - depending on which side of the political debate their thinking fell. What separated their contributions from the purely political ones was that they were using established theories and methodologies of their own disciplines to argue for their case. The scientific validity of these claims was something that could be assessed against their theoretical background. Purely theoretical, conceptual or descriptive bioethics aside, everything in bioethics is political. At its core, bioethics is about rights and responsibilities, justice and entitlement - all of which are political notions.

What has further blurred the line of academic bioethics and political bioethics has been the emergence of interdisciplinary bioethics. When

results from various disciplines are combined to argue for a political cause or position, it is no longer clear how the scientific validity of these contributions can, or should be, assessed. There is no established theoretical or methodological framework for interdisciplinary bioethics. And in the absence of that, bioethics has become politics. In my presentation I will present examples (real and fictional) to offer further support to my claim.

Models of occupational medicine practice: an approach to understanding moral conflict in "dual obligation" doctors[1]

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In the United Kingdom (UK), ethical guidance for doctors assumes a therapeutic setting and a normal doctor-patient relationship. However, doctors with dual obligations may not always operate on the basis of these assumptions in all aspects of their role. In this paper, the situation of occupational physicians in the UK is described, and a set of models to characterise their different practices is proposed. The interaction between doctor and worker in each of these models is compared with the normal doctor-patient relationship, focusing on the different levels of trust required, the possible power imbalance and the fiduciary obligations that apply. This approach highlights

discrepancies between what the UK General Medical Council guidance requires and what is required of a doctor in certain roles or functions. It is suggested that using this modelling approach could also help in clarifying the sources of moral conflict for other doctors with "dual obligations" in their various roles.

The aim of this paper is to show that by using the modelling approach in Occupational Medicine, it becomes evident that not all Occupational Physician-Worker interactions fit this assumption. On the one hand, in model 1 (as will be described in the presentation), the Occupational Physician-Worker interaction is close to the normal Doctor-Patient Relationship, and therefore not surprisingly most of the ethical constraints in a normal Doctor-Patient Relationship make sense in model 1. At the other extreme, when the interaction is very "arm's length" (model 2), most of the underlying assumptions used in the normal Doctor-Patient Relationship are incorrect in that situation. The fiduciary obligation of undivided loyalty, for example, is totally incongruous if applied in a context where *independence* is essential. In model 2, the ethical requirement (by the GMC) for the Occupational Physician to offer to show his report (of an independent assessment) to the applicant before submitting it to the employer or pension fund manager would be akin to a judge offering a defendant first sight of his judgment, and requiring the defendant's consent before delivering it.

[1]*Medicine, Healthcare and Philosophy,* Digital Object Identifier (DOI) 10.1007/s11019-012-9426-4, 2013, 6, 3, 499-506

What kind of power is biopower, and can the notion help us settle normative issues within public health?

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Power relations seem to exist everywhere: between men and women, teachers and students, doctors and patients, employers and employees, authorities and refugees, and between the state and its citizens. These relations can take many forms, from violence and coercion to more subtle influences in the shape of rewards, persuasion, authority, and manipulation. Power can be visible, as well as invisible, as is the case of some structural forms of power. Certain norms and values appear to be important forms of power, not least those that are ideological and political. Even scientifically produced knowledge can be seen as a kind of power, in that it creates new "forms of life" that categorize the world in ways that make people behave and see themselves in new ways. Some of these forms of power appear legitimate, as when a democratically elected government creates new laws, whereas others seem to be illegitimate and immoral, as when minorities are prevented from practicing their religions.

Biopower seems to be a particular form of power, one that concerns the whole population and that emanates from the government and its civil servants. It is not completely clear, however, how this kind of power relates to other kinds of power, or even if it should count as a kind of power. The aim of the paper is, thus, to try to disentangle this issue by, first, specifying what biopower is usually taken to mean, and then comparing it to other conceptions of power, such as "power to", "power over", "social power", "structural power", and "discursive power", and investigating in what forms it might manifest itself, that is, if it is "exercised", as, for example, influence, coercion, manipulation, incentive, or persuasion. Finally, since biopower is claimed to be related to the health of populations, a few cases from public health practice and health promotion interventions will be discussed in order to try to determine if, and how, they might be examples of biopower, as "defined" in the text. This will give us a possibility to evaluate the normative utility of the idea of biopower, and to determine if it adds anything valuable to the critical discussions of these kinds of interventions.

An Anthropo-Ecological Narrative of Health and Being

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The disease-focused medical model has been much criticised for being linear, too focused on acute illness and for its inability to effectively address chronic health problems or multimorbidity where management rather than cause-effect relationships is important. It is generally accepted that good health depends on more than biological efficacy, but to date, and despite a range of suggestions, no viable alternative to the medical model has been identified.

In this paper I will argue that understanding human health may require a range of models or narratives rather than a single omnicompetent explanation.

In the second part I will outline an account of productive human agency as a narrative that recognises human being within an ecological context. Starting from the premise that human health is entailed by living well, it will be argued that effective relations between a person and their environment as well as between body parts, are fundamental to maintaining health through adaptation to changing conditions. Although this is widely acknowledged theoretically, it hasn't been well developed into praxis. By describing a person's productive agency in terms of capacity, utility, external resources and responsibility, an anthropo-ecological narrative of

human health and being is proposed to address some of these issues and offer a framework for understanding the role of primary care that has the person firmly at the centre.

Ethical analysis in clinical years: ethics rounds, acibadem university experience

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Introduction: at Acibadem University School of Medicine, medical ethics and bioethics are integrated in the curriculum in phase one (year 1-2-3) within the professionality programme entitled "Clinical Medicine and Professional Skills (CMPS)" in form of a "Medical Ethics & Humanities" track and in phase two (years 4-5-6) within the clinical clerkships as "Ethics rounds".

Aim: The ethic rounds aim to develop ethical sensitivity and professional motivation during the clerkship period by fostering professional and ethical values in clinical and ethical decision-making in daily practice; to integrate ethical formation in preclinical years with the practice based clinical experience with actual cases.

Materials and methods: Ethic Rounds are featured within the internal medicine clinical clerkship, which takes place four times

within the academic year, rotating groups of students. Additionally, Forensic Medicine inserted Ethics Rounds in the Clerkship curriculum in the 5th year. Thus, five ethics rounds are organized.

The ethics rounds are organized in an interdisciplinary manner with clinicians from different branches. Presented cases may feature different themes working together with the department of medical ethics. The clinicians are asked to choose a case representing an ethical dilemma from their daily clinical practice. They are provided with a guide to prepare this case for discussion with the students during the ethics round. The format of this guide includes a short case description, formulation of the problem and identification of the related ethical values and/or principles. The clinicians are also provided with a short theoretical outline about ethical values and principles.

Results: The students described the ethics rounds as beneficial, remindful, stimulating, and proposed repeating these exercises in each clinical year. They think this practice has stabilized what they have already learned in ethics lessons at preclinical years. They find it instructive to think over the clinical case in the perspective of ethical issues and legal practice. They liked that the cases were chosen from the real daily clinical practice. They enjoyed to express their ideas and views actively and in an open way with peers and clinicians and instructors. They commented that they glean ideas, take lessons from

the clinicians' experiences for managing difficult patient encounters and breaking bad news.

The clinicians find the ethics rounds beneficial. They think that the systematic real life experience such as ethics rounds at undergraduate level will be quite helpful for students to get ready for coping with the ethical dilemmas and conflicts in professional life.

Conclusion: Ethics Rounds are sustainable and compatible with the vertical integration in medical education in order to enhance professionalism.

Sources:

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The meaning of quality of life assessments

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Sometimes, the prognosis of a patient is so poor that the question whether one should refrain from treating the patient is a pertinent one. If the future quality of life of the patient is expected to be very low, withholding or withdrawing treatment become options that should be considered. In this presentation, I will discuss the meaning of quality of life assessments. How do quality of life assessments indeed give meaning and legitimacy to life and death decisions? What does quality of life assessments mean in the first, second and third person singular? Which intuitions are at work in making quality of life assessments meaningful? In dealing with these issues, I will examine the merits and shortcomings of a narrative perspective. My discussion will be in the context of life-and-death decisions in neonatal intensive care units.

Personalized medicine and identity: A narrative point of view

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Possible outcomes of PM touch on basic questions of personal identity: Who am I? Where do I come from? What is my destiny?

Genomic identity means different things, and is coupled with personal identity in different fields and uses: The numerical identification for forensic use, the ascription of predicates in genetic susceptibility for disease, and the narrative identity in predictions of conditions. Moreover, a person's social identity is intimately coupled with genetics in family identity and inclusion in fellow cohorts and patient groups of genetic risk and disease. In this talk I will discuss how personalized medicine can contribute to self-understanding in a narrative form. Genomic and biometric information can advance reductionist and fatalist narratives as well as stories emphasizing kinship and situated freedom. I will suggest that PM has the potential to deepen our understanding and acceptance of ourselves as bodily beings.

The slippery slope arguments against the legalisation of euthanasia. The Belgian example proves them right?

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Belgium – like the Netherlands - has a law on euthanasia since 2002. Euthanasia is defined as 'intentionally ending a person's life by the administration of drugs at that person's explicit request'. Opponents of the legalisation of euthanasia used the slippery slope arguments to

persuade parliament not to allow euthanasia to be performed in Belgium. Parliament was not convinced.

A decade later we are able to see if the opponents were right or not. In this paper I will first focus on what the slippery slope argument is. Secondly, I will address the question if it can be empirically proven that the slippery slope is a fact in Belgium regarding the euthanasia practice.

The slippery slope argument holds that if a proposal is made to accept A which is not agreed to be morally objectionable, it should nevertheless be rejected because it would lead to B, which is agreed to be morally objectionable. The slippery slope argument is often thought of as one argument but it is more accurately understood as comprising two independent arguments: the 'logical' and the 'empirical'. The empirical slippery slope argument means in this case that as a practical matter, euthanasia – as it is understood in the Low Countries and Luxembourg – resists effective regulation. One can try to devise procedures to ensure that it is only performed in accordance with the prescriptions of the law; there will in practice be an inevitable tendency for it to be performed in cases where the prescriptions of the law do not apply and are therefore not respected.

In the debates concerning euthanasia it is the empirical slippery slope argument that is used most at the expense of the logical slippery slope argument. However, in my opinion the logical argument is even stronger than its empirical 'sister'. The logical argument runs that

acceptance of euthanasia leads to acceptance of others forms of killing patients because the former rests on the judgment that some patients would be better off dead, which judgment can logically be made even if the patient is incapable of making a request.

In the second part of this paper I will look at the empirical evidence to assess if the empirical slippery slope argument is a fact in Belgium or not. Robust empirical research has been done (the End-of-Life Care research group of the Free University of Brussels and the University of Ghent; the Centre for Biomedical Ethics and Law and the Center for Health Services and Nursing Research of the Catholic University of Leuven) to assess the end-of-life care consequences of legalising euthanasia in Belgium. The reports of the Federal Control and Evaluation Committee Euthanasia will also be used (it is required by law that every physician performing euthanasia has to sent a completed form after each euthanasia case to this Committee).

Child's Assent in Research: Age Threshold or Personalization?

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Assent is one of the most common ethical and legal requirements of paediatric research. Unfortunately, there are significant differences between the guidelines on the details of assent. What often remain

unclear is the scope of the assent, the procedure for acquiring it, and the way of determining children's capacity to assent. There is a general growing tendency that suggests that the process of assent should be personalised, that is, tailored to a particular child. This article supports the idea of personalisation. However, we also propose to place limits on personalisation by introducing a suggested requirement of assent starting at a certain age threshold. In some situations RECs/IRBs could change the suggested threshold. A recommended age threshold is likely to serve the interests of children better than ambiguous and flexible criteria for personalised age determination.

I will present several arguments which are in favour of our proposition of modification of assent's personalization: an argument from clarity, an argument from comprehensiveness of social rules, an argument from minimalizing subjective assessment and an argument from efficiency.

Funding was provided by the National Science Center, Poland, DEC 2011/03/D/HS1/01695.

Implications of the Health Equality Perspective for the Right to Health

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Health inequality (or health disparities) refers to gaps in the quality of health or health care across different populations and is generally regarded as a major public health problem and a serious human rights violation. However, the traditional human rights approach, which appears absolutist in terms of individuals and processes, seems to create obstacles to further use of the rights-based approach to achieve health equality, which is concerned with differences in population health outcomes. There are two reasons for this. First, in addition to sufficient supplies of medical products and services, which are the immediate precursors of health care, health inequality can also be described in terms of social determinants. However, under the traditional framework of the right to health, health inequalities are generally evaluated on the basis of "individual/medical model" regardless of the influences of social determinants. Second, since human rights movement and health inequality movement have historically evolved in isolation from one another, the health inequality problem seems to remain exempt from the scope of international human rights law and is regarded as a moral challenge. Policymakers aiming to reduce health inequalities then face problems

to identify the claiming of rights, to explore the state's duties, and to establish a causal analysis of rights violations. Therefore, this paper aimed to analyse the relationship between the right to health and health equality and to explore theoretical challenges on the traditional understanding of human rights law pertaining to "equality of opportunity for people to enjoy the highest attainable level of health. The analysis focused particularly on three dimensions, including the transformation of perspectives on health and disability, the change of definition and context of the right to health, and the establishment of an evaluation mechanism. First, this paper proposed that health model should not confine health to only physical and mental levels because a narrowly defined health model might ignore social factors and consequently bypasses the fact that the impairments of social functioning also impose restrictions on individuals' underlying essential capabilities. Second, this paper proposed that individuals' "substantive freedom" in the form of capabilities (health is one of the essential capabilities) should be incorporated into ethical evaluation, and included among the constituent elements of an adequate theory of equality. Third, this paper applied the new framework to assess the human rights impacts of health care policies concerning reducing health inequality in Taiwan, especially the National Health Insurance (NHI)decision-making mechanism. This paper found that the Taiwanese government failed to reduce health inequalities through action on the social determinants.

Opt-in or Opt-out? Rethinking Providing Life Maintaining Technology to the Oldest-old

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Thanks to public health measures and a higher standard of living, men and women in developed countries nowadays have a historically highest average life expectancy up to and over 80 years old. It is predicted that, by the year 2045, 95% of death will occur between the age 77 to 93, and the average death age will be steadily at 85 years old. For those oldest-old (over 80) people, having completed a full life, it is rational to presume that a peaceful death is something in themselves and their family's expectation. "Death", for most oldest old, is a natural ending of a labored life, a form of liberation. However, what most oldest-old do not know is that modern life-maintaining technology (LMT) has transformed the "final days' into "final years" if they do not clearly refuse (opt-out) LMT in advance. It is well acknowledged that mixed with the worries for malpractice lawsuits, enthusiasm toward medical technology, and moral belief to save life, doctors tend to over-treat oldest-old patients.

Death nowadays is no longer the mercy of God. Rather, you would need a "death-planning" to prevent the medicine from taking away your good death. Taiwan's National Health Insurance spent 30 billion US dollars per year on respiratory care. Among the patients received

such care, 44.2% are aged 80-90 Respiratory Care Center residents. Are they “living”? Don’t their families have the slightest sense of guilt? How long can the NHI sustain such futile expenditure?

This paper argues for a paradigm shift for providing LMT to the oldest-old from the conventional opt-out model to an opt-in model. That is, for people over 80, no LMT should be given without a written “will to live”. To be specific, for people over 80, instead of assuming that a now incompetent patient would want to receive LMT in the absence of clear evidence to the contrary, the assumption should become that since any "reasonable" person over 80 would want to exercise a "right to peaceful death," LMT should be withheld or withdrawn unless there is evidence to the contrary. This new opt-in model will have three advantages. First, it may encourage all the senior citizens and their adult children to talk about life-death decisions frankly and honestly. Secondly, it may avoid painful and futile life-saving procedures and facilitate dying in dignity. Finally, this new paradigm integrates the seemingly conflicting concept of “death” into “life,” because a good life includes a good death.