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Abstracts

HUNTING HEALTH – PREVENTIVE MEDICINE IN A RISK ORIENTED SOCIETY

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The Swedish medical journal, *Läkartidningen*, every week presents two pages with short notices on recent medical scientific progress. These short presentations are predominantly focused on clinical studies, with expected relevance for the practice of medicine. In a random selection of five weeks during the second half of 2010, the majority of these presentations concerned epidemiologically investigated and established risks, linking certain behaviors or physiological conditions to increased risk for future disease.

On the basis of an analysis of these studies, it will be argued that the ethical basis for many of them is weak or non-existent. The implicit assumptions in many of the studies seem to be that human beings are rational maximizers of their own future well-being, who are capable of handling and weighing numerous low grade risks against each other and taking the appropriate steps concerning their own attitudes and life style. Also, it is tacitly assumed that the medical profession and the health care system are capable of taking the adequate measures to deal with these multiple risks by allocating resources, performing numerous screening procedures and motivating change of behaviors – while still respecting the well-being, integrity and dignity of their patients.

I will argue that these assumptions are largely false. The risk culture now increasingly permeating both society and the health care system is seriously counter-productive. It is likely to produce more unhealth than health. It is enigmatic and unfortunate that populations that are leading the most secure lives ever in history are increasingly becoming dominated by existential uncertainty and fear of disease and death. It is urgent to search for an understanding of this, which will only be found if the deeper socioeconomic, cultural and historical forces that underlie our society are scrutinized.

ETHICAL ASPECTS OF MEDICAL PROGNOSIS

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Medical prognosis includes both rational-scientific and irrational components that defy formalization and exact anticipation. It is known that scientific anticipation is using natural knowledge which, in each specific case, gives the largest probability for receiving results correctly reflecting reality and changes taking place in it. Strictly determined events are absent in reference to human beings' state of health as it is practically impossible to take into account all internal and external factors affecting the organism, and to make up simple dependences of these factors with the main functional indices. That is why the role of irrational prognosis is quite great in medicine.

The personal intuition of the physician, the individual reaction of patients to a disease, their psychological states, wishes or unwillingness to be cured may be attributed to irrational components of prognosis in medicine. Just numerous and subjective irrational factors complicate medical prognosis and lead it away from the sphere of especially scientific activity in the direction of personal choice of a man.

Today in Russian clinical practice there are two approaches to the prognosis of the course of disease and their outcome: *subjective* and *objective*. Supporters of the subjective approach affirm that medical prognosis cannot be the object of calculations because it dehumanizes medical activity. The others apprehend possible abuse of prognosis information by insurance companies or employers if these data will become public and are used to the detriment of patient's interests.

Prognosis in medicine besides the demands of validity and scientific accuracy also bears great moral load. And here there are important ethical problems: permissibility of the statement of pessimistic prognosis, concealment of unfavorable prognosis from the patient, right of the patient to the information about his or her health status.

The situation, when the possibility of fatal outcome in a short time is very high, is rather difficult in moral terms. This is one of few cases when clinic practice is defined by just prognostic opinions. Such situation requires non-standard attitude, protection of both a patient and a doctor. Serious moral and legal problems are, on the one hand, the validity of not to helping when, for example, the harm of the treatment exceeds its beneficial effects, and, on the other hand, in voluntary nature, when a patient himself or his legal representatives come to a decision. Medical personnel in our country are afraid to become an object of long judicial proceedings and moral condemnation. This leads to corrupting practice of careless carrying out of reanimation measures or to the refusal to assume responsibility for transportation or treatment of the patient at the risk of fast fatal outcome in the hospital.

Besides, in the situation of unfavorable prognosis the doctor may abuse the right of the patient to refuse treatment, throwing fault on the patient him- or herself for any tragic disease outcome. That is, one more of the main rules of biomedical ethics is violated – it is the rule of informed consent according to which the doctor must give patients a complete, exact and reliable information, notify them on the consequences of possible decisions, give them evidence of the prognosis and only after all that to wait for the patient to freely decide either to continue or to stop the treatment.

Thus, the quality of medical prognosis is a serious bioethical problem which requires from the specialist to come to a considered decision, to weigh the situation in legal, professional and moral senses and, consequently, to increase effectiveness of medical assistance.

CONCEPTUALISING ETHICS IN AN 'UNEXPECTED CULTURAL ENCOUNTER' IN DISASTER MEDICINE

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The concept of 'cultural sensitivity' is pivotal in clinical settings for the ethical treatment of humans in the wake of a natural disaster. A person's society, land, and environment are quickly transformed into emergency zones. This alters the human experience of both the victim, and the health-care professional.

A person becomes a fragment of their country's cultural identity/s and amidst loss and disintegration of familiarity, the ontology of cultural differences between the victim and the health care professional shifts during the reminder of the finiteness of both life and traditions, the symbols of what it means to be human.

The contemporary viewpoint translates a rupture in human experience as trauma, fetching with it a body of psychologically-orientated conceptualisations about human experience. What is lacking is a body-centred approach to a totality of systems. The patient in the unexpected cultural encounter in a disaster zone is in danger of become particularised, and this is emphasised in principalist approaches in ethics, which segregates the individual from context.

The presentation of the human body in the clinical encounter is held in a tension; on the one hand, the immediacy of the situation means that the patient is vulnerable to objectification, whilst on the other hand, the cultural narrative encapsulated by the patient emerges as an entity requiring particular identification and response.

This paper will conceptually construct a scenario of an 'unexpected cultural encounter' between an individual who is transformed into a patient and an environment which is transformed into a disaster. It will examine 4 points: a) the relationship of culture to the individual; b) the relationship of the individual to environment; c) the role of cultural narrative in clinical medicine; and d) the altered phenomenology of time in an emergency setting.

The aim of this paper is to shift the emphasis of ethical analysis to what occurs *before* to the 'unexpected cultural encounter' in the health care setting of a disaster zone. This is not to say that health care professionals should be prepped on various cultural narratives as part of humanitarian aid training. But it is to say that phenomenological relations of individuals, culture, and environments need to be conceptually analysed in the context of developing ethical guidelines that aim to maintain 'cultural sensitivity'.

THE CONCEPT OF BIOPOWER: ITS APPLICATION AND RELEVANCE FOR THE ETHICS OF MEDICINE AND HEALTH CARE.

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Michel Foucault first used the term “biopower” (biopouvoir) in the context of race and racism in his lectures at Collège du France in 1976, and the only occurrence of the term in his published works is in the context of sexuality. The fields of sexuality and race may seem to lend themselves easily to analyses of power relations, because of their history of oppression, marginalization and silencing. However, Foucault’s concept of biopower, and his concept of power more generally, is not about such forms of domination. Power, in Foucault’s analysis, is not merely repressive, it is also creative and productive; it can marginalize, but more often it seeks to normalize; it may silence, but it can also make people speak; and if it is oppressive, it always involves resistance. Biopower, in the sense of technologies for the control or management of human bodies and populations, has its effects not through brute force or physical coercion, but through scientific knowledge, which may more or less directly affect people’s behavior, and through institutions, which use scientific knowledge to categorize and label people, to analyze their nature, behavior and health (both individually and as populations), and to deal with them. In this paper I will first attempt to clarify Foucault’s concept of biopower and then discuss its relevance and use for the ethics of medicine and health care.

DON’T LET THE BEDBUGS BITE: THE CIMICIDAE DEBACLE AND THE DENIAL OF HEALTHCARE

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Although Cimicidae or bedbug infestation is not a new public health problem, it is one that is becoming more alarming among healthcare professionals, public health officials, and ethicists given the magnitude of patients who may be denied treatment, or who are unable to access treatment. For example, many terminally ill and elderly patients, who receive home healthcare, are finding their providers and case managers are refusing to visit their homes if they have known or suspected Cimicidae infestations. The underserved and mentally ill with known or suspected bed bug infestations are often denied transportation, thus preventing them from accessing employment offices, healthcare clinics, libraries, and other public services. Case managers, social workers, and others argue they are unwilling to transport their clients and patients, since the bugs may be transferred to the carpet and upholstery of their automobiles, clothing, and other personal items, thus jeopardizing their own lives and those clients or patients whom they serve. Furthermore, the very threat of transferring the pest to hospitals and clinics

alone has created quite an ethical controversy. Efforts to quarantine and eradicate Cimicidae should be made, but such efforts require costly interventions. The alternative, however, can further exacerbate the already growing problems of injustice, i.e., unfair treatment of patients, inaccessibility of needed resources. Furthermore, while Cimicidae can affect all people, regardless of socioeconomic status, race, ethnicity, gender and so forth, those who are poor or unkempt are typically targeted as suspects, and consequentially, are feared. And, for those who have Cimicidae infestations, these individuals may not only be denied access to healthcare and other public services, but also access to proper extermination services, which may be too costly (e.g., thermal treatments versus pesticide). Lastly, efforts should be made to reduce or eliminate the public panic that is ensuing given that persons who have infestations may not disclose their problem to healthcare providers and others, which will not only compromise the therapeutic relationship, but compromise any public health efforts to resolve this debacle.

In the following paper and presentation, I will use local, national and global cases as a way to examine the aforementioned ethical issues associated with this public health problem. Besides discussing the ramifications of denying access to medical care, among other healthcare justice dilemmas surrounding Cimicidae infestations, I will make recommendations for improving the health and well being of those vulnerable populations who are facing a difficult and growing public health problem that is currently being ignored in medical and public health ethics literature, regardless of increased media attention and unusual habitats of localized infestations, e.g., Statue of Liberty, New York City.

THE EQUITABLE DISTRIBUTION OF HEALTH CARE: AN INSURMOUNTABLE PROBLEM?

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The UK National Health Service introduced over 50 years ago incorporated 2 main principles: free at the point of use and available to everyone based on need, and not on ability to pay. As an organisation, the NHS employs a full-time equivalent total of 1,059,904 staff (November 2010), being the next largest single employer after Indian Railways and the Chinese Army, and will spend over £100 billion in 2011. Year on year, demand has steadily increased as ability to treat has greatly improved due to the availability of more effective and safer drugs, new technologies and improved medical and nursing care. Yet from its outset, there have always been problems associated with resource limitations.

Responses to such limitations have included pressure to increase overall or local funding, but which is understandably tempered by wider national budgetary constraints or to seek efficiency savings or to ration services. This has resulted in harrowing examples of delays and some patients being unable to access the best available treatments, particularly when novel and invariably expensive. The National institute for

Health and Clinical Excellence (NICE) was set up to adjudicate on matters of effectiveness and comparative value, but has often been associated with controversy when its decisions do not accord with the views of patients` special interest groups and in the many examples where availability is associated with a location-dependent “post code” lottery. When resources are limited which offers the better option, undertaking many hip or knee replacements or providing a much smaller number of treatments with an experimental drug for a life threatening condition? Who decides and by what criteria?

Numerous papers have been written on the subject of the problems of equity, fairness and justice in health care. The British philosopher Stuart Hampshire suggested in the Tanner Lectures on Human Value of 1996 that “(concepts of) (j)ustice and fairness in substantial matters, as in distribution of goods ...will always vary with varying moral outlooks and with varying conceptions of the good”. The paper will consider the validity of Hampshire`s assertion in the context of the distribution of health care, drawing on the work of Norman Daniels, John Rawls, Michael Sandel and Amartya Sen.

WELL-BEING OF THE CHILD AND THE CONCEPT OF AUTONOMY

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Western legal systems take the right of the biological parents to take care of the child ("child custody") as a natural right. Parents are autonomous concerning the rearing of their children. Constraining the child custody of the parents by the state is only justified in cases of reasonable suspicion that the well-being of the child is at risk. This requirement has its merits although it leads to problems in medical contexts. On the one hand, physicians are responsible for the health of the children they treat as their patients. On the other hand they are bound to the child custody right of the parents. This can lead to conflicts of duty when the physician is confronted with cases of harmed children when there is evidence that the parents caused the harm. In such cases, the physician is confronted with two conflicting duties: first the professional discretion against third-parties, second the duty concerning taking care of the wellbeing of the child. I call this the "family dilemma". This situation is a dilemma because both duties operate on the same level, and it is not always clear for the physician which one he should follow. In other words: What is overriding here: the right of the child to wellbeing, or the parents' right to autonomous child-care? Hence I think a careful ethical analysis of the notion of well-being of the child is utterly important. Such an analysis can help clarify the just mentioned dilemma-situations because it helps defining the status of the child's right in contrast to the rights of parents. From the ethical point of view the well-being of the child differs from the well-being of adults by the child`s lack of autonomy (or rather because children are yet not autonomous persons).

Autonomy is thereby not only a capability or disposition but also a fundamental value of liberal societies. Children should be educated as free, responsible, tolerant or open-minded citizens. From this we can infer a right of children to an open future (see Joel Feinberg 1992) In my paper I will first argue that children's right to an open future is at least as important as the parents' right for the custody of their child. I am of the opinion that, in most cases, the child's right and the respective duties of the physician to protect it are overriding over the autonomy-rights of the parents. In a second step, I point out a number of consequences that are implicit in this claim. For example, it can be shown that in many cases, paternalistic actions that authorities exert on behalf of the child are morally justified. Furthermore the role of physicians can be invigorated due to their important function in child protection.

DOCTORS' KNOWLEDGE ABOUT THE LEGAL POSITION OF RELATIVES REGARDING AUTONOMOUS PATIENTS WITHOUT DECISION MAKING CAPACITY

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Aim: According to Norwegian law an autonomous patient without decision making capacity shall be given medical treatment if it is considered to be in the best interest of the patient, and if the patient probably would allow such treatment. If possible health personnel shall get information from the patients' relatives about the patient's preferences according to medical treatment. The decision shall be made by the responsible doctor in agreement with other qualified health personnel. The purpose was to study whether doctors' attitudes and knowledge are according to legal rules.

Method: A strategic sample of 1175 Norwegian doctors, specialists in internal medicine, paediatrics, surgery, neurology and neurosurgery received a mail questionnaire about end-of-life care in hypothetical scenarios. Recipients were randomly selected from the membership roster of the Norwegian Medical Association. 640 doctors (54.5%) responded, of these 406 had experience with end-of-life decisions. The case presented here concern an 86 year old woman who has been self-sufficient. She arrives at the hospital with a massive *haemorrhagica cerebri*. She is not reachable, but she breaths by herself and gives weak responses to pain. Computerized tomography shows comprehensive changes in her brain. Her only son expresses that she shall not receive active life-prolonging treatment. He has not discussed the issue with his mother but he believes she would agree. The doctors were asked to state their position to the role of relatives in such situations.

Results: 19.3% of 393 doctors stated that relatives in such situations *always* could refuse life prolonging treatment, 59.3% were of the opinion that relatives *sometimes* could refuse life-prolonging treatment, and 21.4% stated that relatives *never* could refuse life-prolonging treatment.

Conclusion: The answers indicate lack of general legal knowledge among Norwegian doctors. If the doctors' answers should conform completely to law, they all should have stated that relatives in such situation never can refuse life-prolonging treatment; to leave the consideration of the patients' interest and presumed consent to relatives leaves the doctor at legal risk. According to Norwegian law the role of relatives in such situations is limited to make an expression about what they believe the patient would have wanted if she had the possibility to tell.

MEDICAL NEUTRALITY IN THE ERA OF MILITARY HUMANITARIAN EXPEDITIONS TO DISASTER STRICKEN AREAS.

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The concept of medical neutrality was born in the nineteenth century in the context of conventional war between armies of sovereign states, at times when medical care of the wounded hardly existed in any format. In the past few decades more and more military expeditions are sent to disaster stricken area and find themselves in very different situations – failed states, "asymmetric conflicts", civilian population and even hostilities. In this presentation we will try to trace the development of the notion of medical neutrality in international law, as well as the evolving seemingly paradoxical notion of "humanitarian wars" (the titles given to the USA invasion to Iraq and the current NATO operations in Lybia) in order to find out whether space for medical neutrality is still possible in such scenarios.

SOME POTENTIAL CONFLICTS WHEN PHYSICIANS ARE ALSO RESEARCHERS

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In her recent book, *The Immortal Life of Henrietta Lacks*, Rebecca Skloot chronicles the story of the development of the commercial HeLa cell line, used in the development of the polio vaccine, in cancer research, and many other important and lucrative research efforts of the past sixty years. This cell line began when treating physicians took, without consent or notice, a sample of cancer cells from Henrietta Lacks and began the first long-term, sustainable human cell research line. The web of ethical, social, and economic issues that arose from this one case illustrates some of the potential conflicts when treating physicians are also clinical researchers.

A number of vital issues and potential conflicts have developed with the growth of private-sector physicians serving as principal investigators in clinical research trials. In the United States and increasingly internationally, many of the protocols are implemented through contract research

organizations (CROs) employed by pharmaceutical companies, but many others are carried out by private-sector physicians in individual or group practices, often in coordination with research bases associated with regional medical centers. The set or nexus of issues is complex, involving subject recruitment and study compliance concerns (including subject incentives, informed consent process adequacy, and lack of local PI control over protocol details, including inclusion/exclusion criteria), economic incentives and identity questions for the physician-PI, and control over and reporting of study results (including study-wide PI knowledge of adverse event reports, and centralized versus local IRB review and control).

The shift in the United States from academic medical center-located clinical pharmaceutical research to private-sector physician-based sites raises questions regarding the effects of the shift on the scientific quality of clinical trials results, on ethical practices for the physician-researcher and the patient-subject, and on the economic and social consequences of the change, including its relationship in several countries to changes in private-sector physician compensation structures over the past two decades. For international research organized and funded by European and American-based pharmaceutical companies, the increasingly international or trans-national nature of clinical research in the past decade has magnified the potential conflicts.

One example of the economic and social issues raised by the increasing globalization of such research, especially in the past decade, is an effort by pharmaceutical companies (and facilitated by CROs) to reduce research expenses and the incentive structure (and potential problems) this creates. One recent report identifies a cost-savings of 40-50% for pharmaceutical studies conducted in China or India over studies conducted in North America or Europe.

In this presentation, I will discuss several of these issues, briefly reviewing the development of the potential conflicts, especially in the past decade. I will focus on the role of Institutional Review Boards and other “gateway” committees in protecting research subject interests and patient care, reviewing several actual (anonymized) examples of conflicts between physician as researcher and physician as health care provider. I will suggest mediating practices that may alleviate some of the potential problems while acknowledging the remaining—and increasing—structural conflicts in modern research.

WHAT IS ALTRUISM IN MEDICAL PROFESSIONALISM?

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The last decade has witnessed a renewed attention of the concept of "Medical Professionalism" and associated values. One central text underlying this discourse is the “Medical Professionalism Charter”, published in 2002 by a panel of international experts.

One of its core principles is the moral commitment to altruism – placing the good of the patient **above** one's own. This is a more demanding standard than mere "Humanitarianism" (adopting the good of the other as a value). In the charter, professionalism is construed as a series of "responsibilities" and "commitments", which are based on three fundamental principles: Primacy of the patient welfare, Patient autonomy, and Social justice. The first principal is defined as the dedication to serving the interest of the patient, and Altruism is mentioned as the basis to the unwritten contract between the patient and the physician.

In parallel to the new professionalism discourse, special attention is directed to the functional hardships faced by physicians as the result of "Burnout", causing a substantial decline in motivation and in quality of clinical work, compromising wellbeing (emotional and physical) and satisfaction. One of the most troubling consequences of physician burnout is the reduction in the quality of patients care.

In search for an equilibrium between the social demand of the Medical Professionalism for Altruism, and the psychological demand for physicians' self-care and wellbeing, this presentation aims at clarifying the call for "Altruism" in medical education. Based on Psychologist Sternberg theory of wisdom, we seek a unique balance of self-care and care for others as expressive of medical altruism.

THE ALLOCATION OF HEALTH RESOURCES AND A PHILOSOPHY OF LIMITS

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Access to basic health services in contemporary society is a fundamental need. The limited availability and the high cost of health care have resulted in the inability of many, often the least advantaged, to obtain meaningful access to basic health care.

Priorities based on marginal, material and economic values have displaced priorities based on more fundamental human needs and values. Societal expectations, entrepreneurial forces, the emphasis on high tech medicine and the increasing specialization within the health care professions are major factors that have contributed. A decrease in infant mortality, the control or elimination of infectious diseases with an increase in the life span has begun to create even greater concerns in some countries. Priorities based on marginal, material and economic values have displaced priorities based on more fundamental human values.

There is typically an acceptance, at least in principle, by political entities of the mandate to provide access to basic health care. At the same time there are other societal needs, such as housing, education, adequate food, sanitation and clean water that require a significant allocation of resources.

An alternative approach that emphasizes vernacular values and the acceptance of limits will be presented. Specific solutions will be offered. The work of Daniel Callahan, Ivan Illich, E.F. Schumacher, Jacques Ellul, and others will be cited.

JUSTICE AND PRIORITY-SETTING IN US HEALTHCARE: WORSE THAN CHAOS

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Health care in the U.S is in veritable chaos. There's no "system"; instead, there is a patchwork of independent subsystems. There are federal systems like Medicare, the Indian Health Service, and the Veterans Administration. There is Medicaid, the federal-state partnership to provide health care for the poor. There are for-profit providers or payers like Humana, Aetna, and UnitedHealthcare. There are large non-profit systems, like Kaiser, Intermountain and Geisinger. If this mélange of systems worked together, providing integrated and mutually reinforcing possibilities for choice and experimentation, the U.S. might be an example of creative chaos. But it is not.

In this paper, we outline briefly at least three ways in which the U.S. system is "worse than chaos": 1) as is widely recognized, the U.S. leaves many people without any coverage at all; 2) the U.S. is addressing the problem of increasing costs (faced by all advanced industrialized countries) in a problematic manner; 3) several important features of health care in the U.S. make it unlikely that U.S. health care will approach any form of justice with respect to setting priorities in the near future. Although we hope that health care reform will lead to some improvements, we also fear that these features of U.S. health care will continue to pose significant roadblocks to effective reform.

HUMAN ENHANCEMENT AND THE GOALS OF MEDICINE: INTRODUCTION

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Increasing scarcity of resources, efforts to contain costs, rationalization – these themes currently frame a lot of health care policy and ethics debates in many countries. Discussing the ethical implications of human enhancement seems odd in this context, like a luxury item amongst more pressing issues. Yet discussing human enhancement is an opportunity to not only to anticipate future developments in medicine but also to confront ourselves with the role of health care and physicians in an increasingly competitive, achievement- and performance-oriented society. This symposium reflects some of the work of the Working Group on Human Enhancement of the Swiss Academies of Sciences and related projects, which will be presented and put up for discussion

INTRAMURAL CLINICAL RESEARCH FOR CANCER THERAPY: TACKLING THE ETHICAL CHALLENGE

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The number of new drugs that make it to the market each year is low. On average, FDA approved only about 24 new molecular entities and new biologic licenses each year from 1999 to 2009. Cycle time for drug discovery is increasing, mainly due to the fact that research is focusing on the very molecular mechanisms of diseases, thus requiring extensive validation efforts to generate suitable new targets. Recent estimates show that it currently takes about 13 years to put a new drug on the market (ref. <http://kmrgroup.com>).

The causes of such a state of affairs are multiple, and some need to be mentioned, even though their analysis is beyond the scope of our paper. Difficulties in drug discovery are mainly due to two classes of causes: technical and regulative. We will give an outline of both in our paper.

Among the proposed solutions, many focus on innovative business models. In-licensing and out-sourcing are widely recommended strategies for Pharma companies to increase their productivity and yield consistent amounts of valuable new products to the market.

If such a model will be able to yield substantial improvements for patients will obviously depend on many factors. Nonetheless, it is important to notice that specific ethical considerations arise from this shift in the global organization of biomedical R&D.

In this paper, we take the IEO-TTFactor partnership as a case study to analyze the bioethical dimension of small intramural clinical research in the context of cancer drug discovery.

Our paper will recall the overall moral framework of current clinical research, its limits and the challenges it might pose to intramural research. We will then introduce our case study and illustrate the possible moral problems it might give rise to. Among them, we will focus on: conflict of interest, informed consent, privacy and research subjects' autonomy. Finally we will propose our solutions to those specific problems and highlight the moral and technical advantages of intramural clinical trials.

MOVING FROM RESEARCH ETHICS REVIEW TO RESEARCH ETHICS SYSTEM –A NEW TURN IN THE RESEARCH ETHICS ANALYSIS

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In the field of research ethics, when evaluating quality standards, the focus was often on the quality of institutional review board operations in order to examine whether policies and procedures result in a coherent, effective scheme for the protection of research participants.

However, Hyder and al. in an article entitled “Moving from research ethics review to research ethics system in low- income and middle-income countries are of a different opinion. The authors are stating that development of effective programs for reviewing research and protecting participants engages wider issues surrounding the general stage of development and democratization of societies and cannot be addressed by regulatory process alone. They are also proposing a framework which links issues connected with research ethics with a country’s societal developmental status. The idea behind their framework is that organizational culture in which research is undertaken affects whether or not ethical conduct is supported and valued. In their work there are proposing a framework which, in their words, can be of use in analysis of the development of the research ethics. We will try to see whether this framework can be useful for the analysis of the Croatian situation.

EXPLAINING THE ORGAN DONATION DECISION-MAKING PROCESS WITHIN INDIVIDUAL AUTONOMY AND SOCIAL SOLIDARITY ETHICAL PRINCIPLES

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Background: Individual autonomy and social solidarity are used simultaneously and in different proportions by the stakeholders of the transplantation field to exhort people to donate their organs. As these ethical principles refer to different theoretical frameworks, psychological and ethical conflicts could raise when people make a decision on organ donation.

Purpose and methods: In order to assess the opinions and the attitudes of people and anticipate the further academic debate, a broad quantitative survey about organ donation was carried out in the Vaud French-speaking Swiss province. In this talk we explore the way in which the values that underlie the rhetoric of the gift, the market logic and the welfare-state model shape inhabitants and physicians organ donation and transplantation social representations and influence the organ donation decision-making process based either on individual autonomy or on social solidarity.

Results: The data collected by this survey show that several elements of the rhetoric of the gift, of the market logic and of the welfare state model are deeply intermingled in the organ donation and

transplantation social representations of the Vaud French-speaking population. Thus, individual autonomy and social solidarity are important values for both groups. However, they are not balanced the same way within groups. On the one hand, physicians seem to be more easily crossed by the public discourses on organ donation and are more sensitive to the cost-effectiveness aspects of the transplantation medicine than inhabitants. They also unanimously consider organ donation a selfless act. On the other hand, inhabitants show to be more reluctant to living and deceased organ donation than physicians. Nevertheless, they are more concerned by a close related person's suffering and are more liable to make a living donation. Furthermore, the analysis highlight that inhabitants are more likely than physicians to emphasize the act of the organ donors by indirect and/or non-financial rewards.

Conclusions: The analysis of these data suggests that several core and peripheral components of the organ donation and transplantation social representation are strained in the French-speaking Vaud population and make the decision difficult for people. We would suggest that encouraging social representations explanation could improve people decision-making process, with respect to the individual autonomy. Further studies are necessary to deepen this issue.

WHAT IS PERSONAL GENOME TESTING? SETTLING THE BASIC CONCEPTUAL QUESTIONS

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This presentation provides an answer to the philosophical question: what is personal genome testing? The answer to this question does not satisfy scientific curiosity alone: it has important implications for the ethical debate surrounding genetic testing for multifactorial diseases. This presentation is not meant to resolve the ethical issues, but rather to clarify some of the basic concepts necessary for doing so.

Personal genome testing is novel in its transparency, its high-level analytical validity, and its direct-to-consumer marketing. Companies are presenting themselves as providers of informational services rather than of medical testing; some explicitly state that the genetic information provided is non-medical in nature. Within the bioethical debate surrounding personal genome testing, the interpretation of certain basic concepts, such as 'test' and 'medical test', has given rise to discussions which are still largely unresolved.

This presentation settles the following three questions: whether a personal genome test is a test; whether it is a medical test; and whether it is a form of genetic screening. It answers all three questions positively. Firstly, personal genome testing companies are not just selling genomic assay results: they provide *interpretations* of that data in terms of relative risks for multifactorial diseases. Although the low levels of

clinical validity do render the validity of the tests *as tests* problematic, personal genome testing companies are indeed putting into the market something more than just genetic data. Secondly, the industry is consistently denying that it offers *medical* testing, so as to fall outside the scope of (European Union) regulatory protocols and medical-professional guidelines. Companies are suggesting that consumers may be driven towards personal genome testing for reasons other than medical: for its curiosity or entertainment value. Whereas consumers' motivations for testing may differ significantly (and interestingly) from traditional patient motivations within the clinical setting, it will be shown that it is irrational to maintain that personal genome testing is not a form of medical testing. Thirdly, there are similarities between personal genome testing services and practices of genetic screening programmes, the most important of which is that they are targeted at individuals who are healthy, for the purposes of disease risk assessment and prevention. Although personal genome testing is not offered by the state but instead by private companies, it can thus be argued to be a form of genetic screening.

Affirmative answers to the basic conceptual questions imply that some of the ethical criteria, norms and values that are used for the evaluation and the regulation of medical testing in general and genetic screening programmes in particular, are applicable to evolving practices of personal genome testing. Examples of such norms and values are quality assurance, availability of treatment or prevention options, proven effectiveness, a favourable balancing of risks and benefits, and professional genetic counselling. Insofar as personal genome testing informs consumers about disease risks, disease prevention, and health management, it entails the same kinds of risks and requires the same kinds of safeguards.

D'OH! DUFF! THE FLAMING MOE!: PERCEPTIONS OF ALCOHOL ON TELEVISION A REVIEW OF THE SIMPSONS

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Alcohol use and abuse among adolescents is a recognised cause for concern in both policy and academic circles. In the UK, a general trend among young people to build their cultural identities and understanding of public health issues, by identify examples from popular (multi-media) fictional representations of those issues. Popular television characters can act as powerful role models, more so than the actors behind the roles. For example, the iconic image of “a martini shaken, and not stirred” is associated with James Bond and not with the actors who portray him.

Furthermore the popularity of such media has been exploited by broadcasters with the added lure of exclusive online content, user generated content and mini series principally produced to improve the ratings of the mainstream media show. The British television show *Skins* has engaged heavily in this paradigm, broadcasting extra episodes and utilising social networking sites. The show has given rise to

the notion of a “skin’s party”, based on the alcohol and drug related behaviour displayed in the show. Media articles have suggested links between the “Skin’s Party” concept and incidents of drunken debauchery among young people.

The Alcopop TV Culture project is investigating this dynamic in order to identify best practices for representations of alcohol and youth violence in popular media. As part of the research process the project team have performed content analysis on the popular TV show the Simpsons, mapping alcohol content and representations, which is then interrogated by key stakeholders to gage the impact such alcohol messages may have on young people and their alcohol consumption. This presentation will showcase some of the initial finding from these activities along with the work of the young participants in outlining new public policy recommendations.

BIOBANKS OF RESIDUAL MATERIAL: RECONSIDERING THE INFORMED CONSENT

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Tissue biobanking of biological residual materials, which constitutes a good resource for medical/science research, has raised some ethical issues, such as the need to define which kind of consent, as expression of donation, can be applicable for biological residual materials biobanks.

These materials can be obtained from surgical activities or from pathological waste material collected for diagnostic purposes. Once the amount of the tissue necessary for immediate or future diagnosis has been preserved, this material can be stored in Biobanks with the purpose of future research.

Biobank research can not be conducted without considering arguments for obtaining donors’ consent: the question is to which extent is it reasonable to require consent in biobank research on residual materials and, if consent is indeed required, what type of consent would be relevant in this context considering the ethical principles of donation, solidarity, protection of donors’ right and science progress requirements.

Regarding the relationship between informed consent and tissue collection, storage and research, we have focused on two possible choices related to the treatment of data and samples in the biobank: irreversible and reversible anonymisation of the samples, distinguishing between the types of residual materials biobank research for which obtaining consent is necessary and justified, and the types of biobank research for which it is not.

The procedures involve different approaches and possible solutions that we will seek to define.

We can assume that with the donation made with an opt-out procedure for irreversible samples anonymisation and the opt-in consent for reversible sample anonymisation we can consider a solidarity

perspective, with proper respect guarantees of the individual and sufficient biological material for research.

In our opinion, starting from the concepts of common good and solidarity, both the creation and the development of residual material biobanks can be obtained in this perspective and maintained through donation. Therefore, informed consent places itself as a balance between the expression of the right of liberty, individual autonomy and society's common good.

However, the difference in the form of consent is justified, in our opinion, by the fact that irreversible anonymization implies a lower risk (in general terms) for the donor, and in a solidarity perspective the silent-assent seems to be enough and to facilitate the process of a direct donation.

In contrast, the reversible anonymization of the sample could represent a greater vulnerability for the donors, regarding privacy violation, return of results ect. and the donation must be explicitly intended and therefore must derive from an explicit consent.

We will further discuss some reasons that can justify our considerations.

CAN MEDICAL HUMANITARIAN ORGANISATIONS CLAIM LEGITIMACY OVER THE REPRESENTATION OF SUFFERING BODIES?

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Medical humanitarian organisations generally draw their legitimacy from informal but tangible sources, such as: implicit moral principles (e.g. distributive justice, collective responsibility); tangible support from attended populations; or commitments to publicity over the process and performance of humanitarian actions.

Representations of suffering bodies through the mass media or other communication vehicles are often seen as necessary to assert such kind of legitimacy. Furthermore, several humanitarian organisations put testimony on behalf of victims (in the sense of 'bearing witness') on equal moral grounds to medical relief. As a result, medical practitioners frequently have to accommodate a clash between traditional medical ethics and claims of humanitarian imperatives, when pictures of suffering bodies are taken beyond the strict needs of medical imaging. I argue that strict respect for patients' autonomy is a prerequisite, but generally not a sufficient condition to solve such moral dilemmas. In many cases, additional deliberations should take place, making explicit all values at stake, and balancing all considerations behind the pictorial display of suffering bodies.

A STUDY INTO HEALTH AND ALIENATION

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“The possibility of abusing health is part of health” (Canguilhem, 2005, p. 133)

Canguilhem’s insight evokes the level of redundancy we are born with, in what regards physiological capabilities: a pair of lungs, of kidneys, an enormous functional reserve for a healthy liver. “To be healthy is to be able to fall ill and recover, it is a biological luxury”. For a healthy human being, to live fully entails the ability to experiment with this luxury: humans are “insatiable beings, meaning that they always go further than their needs”.

There is an insidious risk of judgments about distributive justice, in that there is an implicit commoditization of the outcome, a conflation of resource and outcome into a ‘value added complex’. The result is to look at health as somehow external to the individual, who then becomes responsible before society for the good and his unburdening use of it. Risk taking for one’s pleasure, as a form of self discovery and self-expression becomes a moral wrong, because it risks dispossessing society of the resources invested in that individual. Because society decided to take care of our health, it comes to take possession of it.

The commoditisation of health and the appropriation of health by the state are reducing very significantly the space and scope of self expression, through the moralisation of deep aspects of the private life - those aspects Canguilhem took as defining being human. So, in that respect, we are redefining what it is to be human; we are declaring that no further exploration is needed or indeed morally permitted, the boundaries have been found and established – our lot is now to live within them.

At this point, we must question to what extent the prosecution of welfare and justice is alienating the individual from his health – from himself.

MAY THERAPEUTIC BRAIN STIMULATION ALTER THE PATIENT’S PERSONALITY?

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Deep brain stimulation (DBS) is a powerful instrument for treating motor symptoms of severe diseases including Parkinson, Dystonia and essential tremor. DBS is held to be a safe and effective treatment in well selected patients. However, like every other treatment it is not without side-effects. Some patients report unfamiliar post-surgical behaviour and self-alienation. This talk examines 1st “personality” and “change of personality” as normative criteria for evaluating DBS outcomes and 2nd its impact for the ethical debate concerning other brain interventions.

CO-RESPONSIBILITY, WHAT ABOUT IT?

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In recent publications, I discussed two central notions of contemporary health care discussed: autonomy on the one hand, lifestyle on the other hand. An analysis has been made of the neologism 'oughtonomy' to question the dichotomy between autonomy and heteronomy. Heteronomy, as is argued, is not the dark side of autonomy, and thus something that we should try to eliminate, but rather what 'constitutes' autonomy. Despite the overwhelming consensus about the advantages of autonomy, there are many good reasons to question the widely accepted opposition of autonomy and freedom versus heteronomy and paternalism. All the more, we need to reflect upon the 'disruptive' presence of heteronomy within the principle of autonomy. Consequently, we prefer to elaborate the neologism oughtonomy.

In this paper, I take a next step in this analysis, focusing at a third key concept of today's healthcare, namely responsibility. Personal responsibility is so important today because it is obvious that the way society is organized, many people are facing a lot of difficulties to live their lives in a responsible way. I explicitly obtain an analysis of responsibility from a view which avoids the binary thinking which is so remarkably present in today's health care discourse: freedom versus paternalism, autonomy versus heteronomy, choice versus circumstances, individual versus social, et cetera. This is also the case for responsibility.

My aim is therefore to open up the horizon of the use of responsibility in today's healthcare. I develop the notion of 'co-responsibility' to understand how individuals, despite the fact they are responsible for their own agency, are always also affected by an 'ought' which contaminates their efforts to fulfill their duties and obligations.

I conclude with a plead in favor of a broader framework for handling the question of responsibility in healthcare. By narrowing the field of intervention in advance, the fundamental options are too easily taken for granted. There are alternatives to limiting our concept of responsibility to the results of the personal choices made by an individual on its own. To discuss responsibility in healthcare is to start with co-responsibility, not as conclusion or a magic formula to all problems, but as a new starting point of which we have to explore the opportunities for current and future health care dilemmas.

METHODS TO IDENTIFY HARM IN HEALTH TECHNOLOGIES: AN ETHICAL POINT OF VIEW IN THE EVALUATION OF POPULATION SCREENING.

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Objective: In health technology assessment (HTA) the potential of harm is often neglected or solely presented as a matter of safety while benefit is more likely to be considered comprehensively. Yet, balancing benefit and harm from an ethical point of view and finally reflecting the ethical implications of health technologies adequately is subject to comprehensive information on both benefit and harm on the same level. Therefore, identifying technology-related harm is a crucial objective.

Some methods do exist on integrating ethical issues in HTA but none of these describes in detail how the related harm might be identified. Thus, our aim was to develop a guide to identify possible technology-related harm comprehensively. This includes in terms of ethics the categories of medical, psychological, economic, legal and ethical relevant harm.

Methods: We analysed the previously searched methodological publications on reviewing ethical issues in HTA. Additionally, we systematically searched reviews on ethical issues in health technologies and published HTAs which address ethical issues. We extracted the relevant ethical information and synthesized the issues regarding the mentioned categories. From these results we developed by content analysis a set of items regarding technology-related harm. We selected the items which are relevant to population screening. Finally we applied these selected items on the example of prenatal screening to check their feasibility.

Findings: Our search yielded 9 relevant methodological publications of which 3 addressed the plethora of technology related harm and 198 applications on ethical issues in health technologies of which 28 reports were on screening technologies.

Some of the identified ethical issues are relevant to all population screenings, for instance the consequences of false-positive (e.g. in fact unnecessary subsequent, often invasive, diagnostics), false-negative (e.g. false reassurance, loss of faith in the medical profession / healthcare system) and true-positive (e.g. no effective treatment or no healing prospects are available) screening results. Some of the identified ethical issues are topic-related such as the conflict between the patients' right of not-to-know and the physicians' liability law in prenatal screening. For some topics it is likely that the legal context, bonus-malus systems, societal values or stakeholder interests restrict patients' autonomy and chances to participate in informed consent. In our example of prenatal screening all categories named above are concerned. The most important among them are medical and psychological outcomes on the individual level and economic outcomes on the public level.

All in all 12 items were found to be relevant to identify harm in population screening comprehensively. Four of these questions are not screening-specific, but relevant to all health technologies.

Conclusions: A guide like the proposed might be helpful to identify harm comprehensively, to balance benefit and harm in an adequate manner and to strengthen the integration of ethical aspects in HTA. As mere effectiveness assessment does not uncover all crucial issues sufficiently, e.g. in population screening, an assessment or analysis of ethical issues may assist the decision-makers bring about a decision most beneficent to individuals and the public. This includes more sustainable management of limited resources.

‘SPORT FOR ALL’ AND THE PROBLEMS OF HEALTH PROMOTION

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It is assumed that part of the heritage of the 2012 London Olympics will be an increased popular participation in sport and physical activity, and hence ‘Sport for All’. The elite athletic activities of the Olympic sport are thus justified, in part, by their potential health benefits for the population as a whole. The purpose of this presentation is to question the validity of this assumption, and thus to explore the place that the model of elite sport might have within health promotion.

If the Olympics will impact positively upon levels of physical activity in the wider population, then it must be assumed that elite sport provides an appropriate model and motivation for increased activity. Both of these points can be challenged. It will be argued that elite sport is not a model of healthy activity. The elite athlete pushes their body beyond generally sustainable limits of performance, potentially leading to long-term injury, psychological stress and social dysfunction. The very image of the elite athletic body may be problematic as an image of a healthy body. At the level of motivation, there is little obvious link between the highly specialised and competitive activities of the elite athlete and the forms of activity embraced by the notion of ‘Sport for All’. The use of the word ‘sport’ in the two contexts conceals a fundamental conceptual difference. It may be suggested that the only elite activity that does motivate non-elite participation is the marathon (in so far as it provides a model and aspiration for ‘fun runners’).

In conclusion it will be suggested that, while ‘Sport for All’ appropriately conceived may have significant benefits for the health of the general population, any policy in support of ‘Sport for All’ must be developed independently, and perhaps in opposition to, elite sport.

DRAWING LESSONS FOR EMPIRICAL BIOETHICS: RECENT RESEARCH IN THE ANTHROPOLOGY OF ETHICS AND MORALITY

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Medical sociology and medical anthropology have both offered detailed analysis and interpretive accounts of modern medical culture and its structures. Some of this work has explicitly focused on the ethical and moral aspects of biomedicine and in doing so has offered a powerful, if often implicit or 'cryptonormative', critique of the 'thin' ethics of bioethics understood to be applied philosophical analysis. Such research has, however, not gone as far as to offer a theoretical and conceptual account of 'ethics' and 'morality' suitable for social scientific research focused on the moral and ethical aspects of human life and medical practice. It is obvious that such research does not, cannot and should not methodologically rely on philosophical moral theory or applied ethics schemas at the risk of carrying an inherent normative bias regarding the object of study. Nevertheless it is also unsatisfactory for sociological and anthropological research into bio- and healthcare ethics to merely assert a methodological relativism. At best such research risks being consigned to a handmaiden role where it merely provides facts for applied ethics analysis. At worst such research would appear to equate 'morality' with 'culture' permitting it to become a totalizing concept which places everything under its purview and therefore becomes meaningless. As such we are on the horns of a dilemma: Either empirical research on ethics implicitly accepts the handmaiden model and so untenably maintains a strict distinction between facts and values in social scientific research; or it adopts a radically relativist stance and a positive account and critique of morality becomes lost and reduced to culture.

However within the disciplines of anthropology and sociology more generally there has been a recent expansion of interest and research on morality and ethics. Such research has developed its own distinctive approach to the thick social, cultural and historical worlds it attempts to understand and interpret. This paper will consider recent research in the anthropology of ethics and, to a lesser degree, the sociology of morality with a view to drawing some theoretical and programmatic lessons for bioethical research in this mode. We will pay particular attention to the conceptual cartography of 'ethics' and 'morality' developed by Zigon and consider the utility of this perspective in conducting bioethical research of an empirical nature. Having established that Zigon's cartographic account could be usefully employed by bioethics I shall address the question of whether research conducted according to this methodological schema can offer any greater insight into bioethical practice than the handmaiden model or a culturally relativist stance and how it can be coupled with normative ethical concerns.

THE ETHICAL SELF AFTER GENETICS: DERRIDA ON HABERMAS

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In this paper I wish to raise the question of how developments in the science of genetics, and the debates consequent on them, effect our thinking of the self as well as how certain streams in continental philosophy can help us better think the ethical issues associated with these developments. My intention is merely to raise some questions and open up some previously neglected paths rather than provide any definitive conclusions. I will do this first of all by looking at a recent work Jürgen Habermas has devoted to the subject and then by scrutinising it in the light of a much earlier and neglected contribution of Jacques Derrida to the subject.

IMPLICIT RATIONING AND MARKET-DRIVEN MEDICINE: A DANGEROUS COMBINATION FOR THE PATIENT-PHYSICIAN-RELATIONSHIP

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Health care systems in several European countries are confronted with bottlenecks in supply: Rationing is already an undeniable reality in medical practise and situation probably is getting worse during the next decades so that coping with limited resources will even more be one of the crucial challenges in future patient care.

Already for decades experts on different fields have claimed that if it comes to rationing explicit forms should be preferred. One of the essential disadvantages of implicit rationing is opacity which may leads to unequal treatment and constrains the chance of raising objections. Nevertheless, measures often concentrate on budgeting. This is not only as explicit rationing is unpopular but also as there is a variety of unresolved questions and fears concerning direct restrictions of medical services.

This contribution will strengthen the thesis that arguments against explicit rationing could never be of principal nature because of its genuine aspect of equal distribution of scarce resources. This point gains relevance in the way that disadvantages of implicit rationing are increasingly prevailing possible positive aspects via further tightening of the belt. On the example Germany I will analyse weak points in structure of the health care system that are susceptible for implicit rationing and give examples for emerging complications concerning the physician-doctor-relationship.

One of the main problems seems to be the growing conflict between monetary interests and essential requirements for the patient-physician-relationship. On the one hand health insurances promote their financial interests through linking them to financial interests of the doctor. So “financial outcome” for the doctor depends on decision on therapeutic strategies and payment is quite well predictable, respectively.

On the other hand increasing alternatives of complex treatment (e.g. in oncology or reproductive medicine) make it even more important to inform patients about different options, possible benefits and risks as only integration of personal values, individual situation and preferences can lead to the best decision. Not only lack of time but also conflicts of interest concerning economical aspects of treatment choice can lead to insufficient education of the patient and non-disclosure of relevant information.

Aggravation of the problem arises from phenomenological interferences with the emerging field of lifestyle medicine. This heterogenic market, ranging from curative treatment with clear medical indication to pure wellness-services just falling back on medical knowledge, techniques or only appearance, is growing rapidly at the moment. Due to compensate decreasing business volumes in the health-insurance covered sector marketing strategies are applied in order to promote services of lifestyle medicine. As the service provider can be the same person as the physician, conflicts of interest especially concerning disclosure of information may arise. Strategies like negotiation, marketing and limitation of liability face values like confidence, honesty and assistance in the same consultation. In this way marketing profits from medicine whereas medicine suffers from this kind of practice.

Therefore a mixture of merchandising and medicine has to be avoided as well as implicit rationing must be restricted in order to prevent a confidential patient-physician-relationship.

PRIORITY SETTING IN HEALTH CARE: THE STARTING POINT

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In the vexing debates about setting limits in health care little attention has been paid to a very simple criterion: using *minimum effectiveness thresholds* for rationing. Reservations against enormous efforts in order to gain very small clinical benefits are widespread in the public. On the other hand, and often also by popular demand, offering medical interventions with only minimal effects seems to be part of today's regular medical practice. Reasons for the prevalence of such treatments are manifold: In many Western countries, physicians prescribe these because they are (often wrongly) afraid of legal liability or dread to admit that "there is nothing we can do anymore"; patients dwell on unrealistic hopes; and relatives have trouble to face their loved one's end. We think it is irrational and wrong to ration effective treatments whilst at the same time offering some that promise such low individual benefits for patients.

Minimum Effectiveness Thresholds: A Criterion for Setting Priorities Fairly: Ultimately, all therapeutic and most other medical treatments aim to either prolong patient survival or improve their well-being. Of course, individual patients may come to different subjective evaluations of such clinical results, which they can express in their informed consent or dissent to treatment. Nevertheless, health care systems

rightly assume that most patients welcome extra life years and positive effects on various aspects of HRQOL. Offering medical interventions within a health service is thus, at least in theory, based on the evidence for such objective clinical benefits. They are captured in measuring a treatment's *direct clinical effectiveness*, i.e. its positive causal effects on selected outcome parameters, such as survival, or parameters of HRQOL (reduction of pain, improvement of mobility etc.). However, whilst most health technology assessment studies measure effectiveness, in many studies, other parameters are chosen for evaluation, such as e.g. changes in tumour size, detection rates or a variety of physiological effects. We believe that these parameters are only relevant in so far as they impact on patient survival or HRQOL, and therefore, medical interventions should primarily be evaluated by demonstrating effects on these two parameters.

Our suggestion then is to cut any intervention from publicly funded health care that does not prove to reach a certain pre-defined threshold of direct clinical effectiveness and which is in this sense *minimally effective*. This "razor" should not only cut minimally effective drug therapies, prominent in the media and public awareness, but likewise extend to last resort surgery, behavioural interventions or diagnostic tools. For instance, new imaging procedures like PET-CTs should either be proven to prolong patient survival by more than a minimal length or impact more than minimally on HRQOL, or be excluded from public funding.

Rationing, if pursued transparently, can never be painless, because it amounts to otherwise undesired losses of clinical benefits. However, rationing according to our criterion would arguably distribute such losses in the fairest possible way.

GLOBALIZED CLINICAL TRIALS: EXPLOITATION AND THE DEMANDS OF GLOBAL JUSTICE

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Exploitation is a recurring theme in international research, especially in off-shored clinical trials. However, what exactly counts as exploitation in this context is far from clear in the current bioethical discourse. Some commentators argue that exploitation is essentially a characteristic of specific transactions, regardless of existing background injustices. Others have argued that in order to respond to the charge of exploitation, researchers and sponsors must contribute towards redressing existing injustices.

Using the arguments from global justice theories and emphasizing the central importance of health and health-related enterprises to issues of justice, I argue that actors in this field do have certain negative and positive obligations in the context of international trials that go beyond concerns of micro-fairness, to

attend to macro-fairness and global justice concerns. I specifically compare and contrast the responsibilities of three categories of actors: multinational corporations, gatekeepers (IRBs and health policy-makers of host-countries) and the global citizen.

JUST COMPASSION

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In the discussion about the right attitude of health care professionals, compassion is one of the most important concepts. In nursing ethics as well as in the debate about professionalism of physicians it is regarded as a professional virtue that ensures adequate closeness and warmth in contact with the patient.

Even if we leave aside the concerns that compassion could be a too asymmetric and condescending attitude that is in danger to disregard the dignity and autonomy of the patient and if we take for granted that it is good for patients if the health care professionals are able to meet them with compassion, it still seems to imply problems of justice. Not all patients who need it can arouse our compassion to the same degree. Children, sympathetic, attractive and admirable persons can get our compassionate attention easier than ugly, disgusting, aggressive and condemnable persons. The goals of medicine, however, demand to give good care to all kind of persons, irrespective of their social status or personal merits. If compassion rather endangers than helps these goals, can it be a professional virtue?

I propose to regard compassion as a professional medical virtue, but not understood as a spontaneous emotion that cannot easily be evoked at will. I suggest understanding it as a professional attitude implicit in the goals of medicine and the health care system: an attitude to help patients because of their suffering, not because of their merits or capacities. The background is an idea of man as a sentient and vulnerable, finite being. This goes for ALL human beings and is the basis of solidarity. Respect of human dignity thus does not mean to admire the cognitive capacities or the moral merits of humans (or at least their potential for that), but to accept them as member of a community which knows about our needs and weaknesses and responds to them with mutual help. Understood like this, compassion is implied in the roles and tasks of health care professionals, and is neither over-demanding nor unjust.

TRUTH-TELLING IN CANCER PATIENTS IN A GLOBAL SOCIETY

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Background: Bioethics in its attempt to support the global health reform has got high profile worldwide. Not surprisingly, western conceptions of autonomy inform health laws, policies and to some extent the

medical practice in most societies. A significant case is the disclosure of diagnosis and prognosis in cancer patients. If thirty years ago in most societies, cancer patients were not informed about their diagnosis, now the informed consent is regulated by law in most democratic countries being a moral obligation on health professionals' part to inform cancer patients about their diagnosis.

AIM: To analyse whether it is morally sound to have a global approach with respect to truth-telling in cancer patients.

Method: We reviewed the published empirical and non-empirical articles on truth-telling and autonomy as well as on the relationship between truth-telling and quality of life of cancer patients, to analyse the ethical underpinnings of this global approach.

Results and Conclusions: Surveys from different European countries show that there is a large variation of patients' expectations to know their diagnosis, if they would have had cancer. Whereas in the United Kingdom and Northern Europe most patients wanted to be informed about their diagnosis, people in Mediterranean countries and Eastern Europe expected that their family should be informed. In addition, doctors follow the same pattern as the patients suggesting that they respect patients' autonomy. However, this contradicts with

THERAPY VS. ENHANCEMENT: ADEQUACY OF THE MEANS TO THE INTENDED AIMS.

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One of the most discussed issues in the enhancement debate is the distinction between therapy and enhancement - that seems to already contain a moral preconception - that is often seen as an effort to separate "good" and "bad" strategies, as the US President's Council on Bioethics said (2003).

In our paper, first of all, we will summarize the many causes that lead to the blurring of this distinction. The first one is the indistinct boundary between "normal" and "pathological", as demonstrated in the well known example of the two children Johnny and Billy, both treated with growth hormone to prevent short stature caused by factors not necessarily pathological (Parens 1998, Daniels 2000); other causes are the heterogeneous uses of medicine with aims going *beyond therapy* - cosmetic surgery, eugenic selection etc. -, the phenomenon of "medicalization", and the effects of "improvement" and "empowerment" due to regenerative medicine, prevention and so on.

However the most difficulties in discerning between therapy and enhancement arise from the even more complex relationship between "health" and "well-being", two terms that the World Health Organization has decided to weave together in a problematic way. This way, in the example of Johnny and Billy "pathological" is what makes the children incapable to reach a full state of well-being, but it is

appropriate to ask what are in this and others cases the real incapacitating factors. In our opinion it is necessary a coherence among the causes that lead to a request of treatment, the intended objectives and the treatments themselves.

The main objective of our paper will be to assess the *adequacy* of the means compared to the intended aims, it is fundamental to recover some normative criteria: it is, therefore, necessary to define what we mean by “health”. Health, on the one hand, is connected with the person being complex, corresponding to an organic, relational and spiritual equilibrium. On the other, it is possible to define health in terms of three types of criteria, namely 1. objective - clinical and scientific data -, 2. subjective and 3. socio-cultural criteria.

It is opportune to observe that technological means can operate only on objective factors that are organic and biological, whereas requests for enhancement generally come from psychological and social needs, as shown in Johnny and Billy’s case.

Subjective reasons for distress, particularly if not connected to a pathological condition, require *primarily* different kind of interventions, such as psychological or spiritual support and broader interventions in social issues. *Secondly*, it could be useful to look to technological means with a comprehensive approach regarding the person.

This kind of approach doesn’t establish whether the use of enhancement technologies is ethically permissible or not: we consider, however, that it provides a criterion to assess the consistency of *enhancement* in relation to the purposes for which it is promoted, that have to be reconnected with the global reality of the person.

JUSTICE AND CONTEXT: WHY WE DO NOT HAVE TO ADHERE TO JUST ONE THEORY OF JUSTICE.

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Appeals to social justice, as a means of persuading that medicine and health care should have certain priorities and not others, are common. However, it is important to note that there are many theories of justice and sub-theories. There are utilitarian theories, libertarian theories, and egalitarian theories. There are also the so-called luck egalitarians, equality as fairness thinkers, and capability theorists, with each having its own distinctive approach to the distribution of medical goods and health care priorities.

The paper uses the example of genetic technologies and their potential applications to highlight the different priorities that utilitarian, libertarian and egalitarian theories suggest. The paper argues that not only do the different theories have different priorities, but also that in some cases they would require different interventions in the name of justice. In the absence of any knock-down argument to demonstrate

which theory is ultimately correct, it is unclear how we can know what the requirements of justice are. One possible solution to this impasse lies in the possibility that the different contexts and different specific applications of genetic technologies may justify the application of different principles of justice; some questions will perhaps admit of a utilitarian solution whilst others may suggest a solution that is more egalitarian, or even libertarian. It is argued that one problem with this otherwise attractive view is that it still relies on our intuitions which may not be subject to consensus. Exploring this possibility shows how it is not the case that one has to subscribe to only one theory of justice, but it is still unclear which one is applicable in any given context.

It is true that the advocates of the different approaches do not themselves think that they are merely one amongst many, and arguments are usually offered to support the theories. Nonetheless, since there are arguments and counter arguments on all sides, as well as different intuitions, unsurprisingly, priority setting in the name of justice is always as much a political enterprise as it is an ethical one.

“WHY DIDN’T THEY EVEN MENTION THAT SIDE OF IT?!?”

NEGOTIATIONS OF MEDICAL TREATMENT AND MAINTENANCE IN NARRATIVES OF VAGINAL AGENESIS

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Being told, in adolescence, that you neither have a uterus nor a vagina can be a truly shocking experience. Beliefs about the body and expectations for the future that one previously took for granted may suddenly be overthrown and questions evoked concerning of sex, gender, normality and possibilities of medicine. The suspicion that something might be different most often emerges as the women do not start to menstruate (compare Liao et al. 2006) which is followed by a long round of medical examinations. Commonly these medical encounters involve discussions of treatment options, such as plastic surgery or dilation, meant to create a neo-vagina or to enlarge the vagina to a more ‘normal-size’ (compare Liao et al. 2006).

Previous medical research on treatment of uterine and vaginal agenesis, as well as other conditions included in the umbrella term ‘disordered sex development’, has mostly focused on the anatomical and physiological outcome of specific surgical techniques (Bean et al. 2009; Brun et al. 2002; Communal et al. 2003). A small number of studies have focused on social and psycho-sexual aspects of vaginal agenesis, for example addressing the complexity and barriers of dilation treatment (Liao et al. 2006; Minto et al. 2003; Möbus et al. 1996). In the humanities and social sciences focus has primarily been on the medical management of children with intersex conditions, i.e. infants born with unclear sex (Feder 2006; Gough et al. 2008; Hester 2004; Malmqvist & Zeiler 2010; Roen 2008; Zeiler & Wickstrom 2009).

Only a small number of studies have focused on experiences of being diagnosed and undergoing treatment for vaginal agenesis and similar conditions as an adolescence or adult (Boyle et al. 2005; Holt & Slade 2003).

Using a narrative analysis this paper explores in-depth interviews with ten women who have been diagnosed with uterine and vaginal agenesis in adolescence. Its overall aim is to explore how the women make sense of medical treatment and advice in everyday life. Furthermore, it seeks to problemize how these particular medical interventions intertwine with culturally shared dominant storylines of bodily normality and (hetero)sexual practices in the women's narratives; how may such an intertwinement interfere with the women's attempts to make sense of their situation?

The analysis reveals how the women present their wish for normality as obvious. They say that they do not regret having treatment and take responsibility for maintaining the normality that has been created through medical interventions. Nevertheless, the women concurrently negotiate the medical interventions and the advice they have been given. By attending to how the interviewees in their negotiations challenge dominant storylines of the possibilities of medicine the paper highlights how the interviewees create space for resistance, although situated in a context where few alternatives may seem available.

ADVANCED COPD, OLD AGE AND RESPIRATORY TREATMENT: HOW MAY AN ETHICS OF CARE GIVE BROADER PERSPECTIVE TO PRIORITIES SET AT THE BEDSIDE?

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Background: Chronic Obstructive Pulmonary Disease (COPD) is one of the largest growing chronic illnesses in the western world and is counted as one of the major health problems for the future. In Norway, 7 % of the population are diagnosed with COPD, which increases by 20 000 new incidences per year. The majority of these patients are between 60 and 74 years old. Patients with advanced COPD often become "swinging door" patients, moving in and out of hospital. With a chronic and serious illness they are very much in need of coherent and compassionate health care. In the advanced stages of COPD, the patients' lung functions are deprived and the patients usually develop additional health problems. Many of these patients suffer seriously from their health conditions. When the illness is exacerbated, 20-30 % of these patients frequently need respiratory treatment in an ICU. Deciding whether the elderly patient with COPD will benefit on respiratory treatment or palliative care at the end of life are complex decisions based on individual reasoning. In my PhD research focusing on bedside priorities in ICs, physicians and nurses experienced strongly that there was a growing ethical dilemma that elderly patients with marginal benefits from ICU treatment were given so at the end of life.

Aim: The aim of this paper is to elucidate and discuss value conflicts concerning bedside priorities with regard to respiratory treatment for elderly patients with advanced COPD. Additionally the aim is to shed light on possible perspectives and resources of an ethics of care that is not present in the ethics reflected in the guidelines for health care priorities.

Method: The paper is part of a qualitative research project. Physicians and nurses involved in decisions about whether to treat the elderly patient with advanced COPD on a respirator or not, as well as patients with the illness, previously treated on a respirator, will be interviewed. I will investigate how the healthcare personnel reason and ration ethically in these decisions. Further it is important to find out how the patients experience that issues about respiratory treatment are being discussed with them in a caring and open manner. The empirical data will be interpreted hermeneutically through content analysis. The discussion and theoretical interpretation will be inspired by Virginia Held, Anne Marie Mol and Joan Tronto and center on how an ethics of care may give a broader perspective to the priorities made bedside. The research is part of the international umbrella project "Mapping the normative terrain of an ethics of care", based at the Centre of Medical Ethics, University of Oslo.

Conclusion: In Norway guidelines and regulations for health care priorities are inspired mainly from consequentialist, deontological and principle based ethics. These guidelines provide few answers in establishing priorities for patients with complex and advanced chronic illnesses at the bedside. Values like care and compassion for the particular and concrete patient is imperative for good and right priorities at the bedside. This again raises a need for an alternative ethical approach, represented by an ethics of care. An ethics of care seems appropriate not only to capture concern for all involved parties, but also for the particular and concrete patient that the physicians and nurses are caring for

"WHAT DO YOU THINK OF PHILOSOPHICAL BIOETHICS?"

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The following exchange reportedly transpired between a journalist and Mahatma Gandhi.

Journalist: Mr Gandhi, what do you think of Western civilization?

Gandhi: I think it would be an excellent idea!

Ask me what I think of philosophical bioethics and I will give you the same answer.

Bioethics studies a variety of topics from a number of different angles. Its main topics can be found within medicine, healthcare, scientific research, and ecological considerations. Its primary approaches are provided by professional self-regulation, legal regulation, social sciences and the humanities, and philosophy.

Philosophical ethics (without the “bio” prefix) has its own sets of methods. The most important of these include the formulation and application of moral and political theories; moral anthropology and sociology; and metaethics in its various forms. Moral anthropology and sociology, as I understand them, examine the presuppositions of our ethical thinking, such as the freedom of the will, the egoism and altruism of the human nature, the relationship between individuals and communities, and the meaning of welfare, happiness, rationality, and virtue in our lives. Metaethics studies stances on the meaning of moral sentences, rules of reasoning and their proper use, and views on the correct interpretation of fundamental concepts, principles, distinctions, and arguments.

Philosophical bioethics, as it is currently practiced and taught, is often limited to the application of traditional moral concepts, principles, and theories to contemporary “bio-issues”. This leaves several worthy questions unanswered, as pointed out, for instance, by two presidents of the European Society for Philosophy of Medicine and Health Care. On a general level, Tuija Takala has asked whether bioethicists, philosophical or otherwise, want to limit their activities to being demagogues, firefighters, or window dressers (Tuija Takala, “Demagogues, firefighters, and window dressers: Who are we and what should we be?” *Cambridge Quarterly of Healthcare Ethics* 14 (2005): 385-388). And Søren Holm has questioned, on the metaethical level, our willingness to employ parity-of-reasoning arguments (“if you think that this is acceptable, you must also accept that”) unquestioningly in support of our views (Søren Holm, “‘Parity of reasoning’ argument in bioethics – some methodological considerations”, Matti Häyry and Tuija Takala (eds), *Scratching the Surface of Bioethics* (Amsterdam and New York: Rodopi, 2003): 47-56).

In this presentation, I aim to sketch some of the most important lines of enquiry that would enable philosophical bioethicists to move beyond the mechanical application of preconceived ideologies and to bring philosophy as a commitment to open and discursive reflection to bear upon bioethical thought.

DIGNITY AND DEMENTIA CARE

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Due to ethical difficulties, there have been few qualitative studies which have included people with dementia as participants. The aim of this study was to include persons with dementia in research and find out how they and their proxies experience dignity in nursing homes. In this paper only preliminary findings will be presented. The study is based on participant observation in two Norwegian nursing homes, and on in depth interviews with five patients suffering from dementia, and six proxies of patients with dementia living in nursing homes.

Preliminary findings show that persons with dementia suffer from home-sickness, they do not experience the nursing home as their home, and do not always understand why they have to stay in the nursing home.

They experience an “empty life” with little social interactions with others. One of the participants told about a feeling of “being in a prison without bars”, not only because of the locked doors, but also because of the feeling of being totally dependent of the staff and their time and priorities. They also felt that the staff was busy, and they were afraid of disturbing the staff in doing their work. They felt that their physical needs were met, they got food, clothes and a place to stay.

The proxies experienced the nursing homes as a safe place for the persons suffering from dementia. Their physical needs were met, and they were secure. They told about difficult, unsecure and undignifying situations when the patients still stayed in their home. And they told about how they had to fight for the patients, to get a place in a nursing home. But they also felt that there was a lack of resources in nursing homes and that the staff in the nursing home had little time for each patient. The material will be further analyzed and discussed up on theories about dignity and linked to justice and access to 'proper' health care as a human right for persons with dementia.

ECONOMISTS SETTING PRIORITY: ON UNJUST PRESUMPTIONS IN COST-EFFECTIVENESS ANALYSIS.

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In modern health care priority setting is oftentimes based on health technology assessments (HTA) including economic analysis. These analyses are based on more or less advanced economic and mathematical models and present their results in an objective fashion in terms of health outcome per cost. However, the various methods are based on a series of normative presumptions that are seldom made explicit. This tends to cover important normative premises for public debates on priority setting in health care. This paper will review some of the basic economic theories in HTA and highlight some of the normative premises and problems with the various approaches. In particular it will investigate their implications for justice. It will be argued that several of the standard methods applied presume models and theories that have unjust implications.

PRIORITY SETTING IN HEALTH CARE: SOME SCANDINAVIAN EXPERIENCES

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The Scandinavian welfare states have public health care systems which have universal coverage and have traditionally had low influence of private insurance and private provision. Due to raises in costs, elaborate public control of health care, and a significant technological development in health care, priority setting

came on the public agenda comparatively early in the Scandinavian countries. The development of health care priority setting has been partly homogeneous and appears to follow certain phases. This can be of general interest as it may shed light on alternative strategies in health care priority setting. This paper will investigate the similarities and differences in priority setting between Sweden, Denmark and Norway. In particular it will highlight the regulation on the macro, meso and micro level, the fluctuation of foundational ethical principles, the variable importance priority processes and organizations, as well as some general trends in priority setting in the Scandinavian countries.

THE CONCEPT OF JUSTICE AND THE NEED FOR PRIORITIES IN HEALTH CARE

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This paper will provide an analysis of two questions: 1) is there a need for setting priorities in health care? And 2) if there is a need for setting priorities what role should considerations of justice then play? The paper will first sketch a simple health care system where there is no need for setting priorities at a collective level. It will then look at different 'additions' to this simple system that give rise to a need for priority setting and ask whether or not they raise issues of formal or distributive justice. The conclusion of this analysis supports two conclusions 1) there is a need for setting priorities in health care in all modern health care systems, and 2) considerations of justice must play a role in priority setting, but other considerations are important as well.

ENGAGING VIRTUAL PUBLICS IN ETHICAL DEBATE

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It is important for (political) decision makers to be able to engage publics in debate about ethically contentious issues. It enables the decision maker to gauge the mood of the public and it adds validity and legitimacy to the decision making process. Such public discussion often relies either on methods engaging a small part of the public as representatives (e.g. consensus conferences) or engaging interest groups. But is it possible to engage publics that are trans-national and where interest groups are only loosely organised on the internet?

This paper will discuss the approach taken by the EU sponsored TECHNOLIFE project (<http://www.technolife.no/>). One aim of this project was to investigate if and how it is possible to engage virtual communities on the internet in discussion about ethical issues related to the kind of practices or interests they have coalesced around.

The paper will outline the general TECHNOLIFE methodology and present results from the “Implications of body and mind enhancement technologies” part of the project (<http://body.kertechno.net/>). It will be argued that it is possible to engage transnational publics in meaningful ethical debate, although a number of limitations of the TECHNOLIFE approach will also be mentioned.

WHO BUYS HYPOTHETICAL INSURANCE? A CHALLENGE AND A SOLUTION FOR INSURANCE BASED LUCK EGALITARIAN APPROACHES TO DISTRIBUTIVE JUSTICE IN HEALTH CARE

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Luck egalitarian approaches to distributive justice have come to dominate much contemporary debate of distributive justice in political philosophy. Two versions of this approach have been outlined in the context of health care distribution - the prudent insurance model proposed by Ronald Dworkin and the luck egalitarian approach proposed by Shlomi Segall. One problem that the prudent insurance model faces is that its central device is to imagine someone making a decision about insurance against their future health care needs, however it is unspecific about at what stage in their life we should imagine them making this decision. Dworkin highlights this and suggests perhaps we should conceptualise them at 25 - but this is not definitive, nor is any justification of this offered by Dworkin, he notes in a footnote that this ought to be followed up but has as of yet not done so. Throughout his work he seems to conceptualise decision makers at very different life stages each buying insurance with very different outcomes - most strikingly in regards to the question of health care for severely disabled newborns he asks us to imagine parents making insurance decisions for the whole family and thus not paying very expensive premiums for very poor outcomes, but when he looks at child benefits he asks us to imagine the child pre being born choosing to buy insurance against having destitute parents! This obviously comes up with very different answers, and begs the question how should we conceptualise the chooser in prudent insurance theories? In this paper I develop a coherent approach to this question and aim to show that this protects Dworkin's approach from some of the criticisms that have been offered against it. Hence this allows us to develop an alternative luck egalitarian approach to distributive justice in health.

EMERGENCY SITUATIONS ON GREEK ISLANDS: THE CASE OF UNNECESSARY AIR MEDICAL EVACUATIONS

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Greece is a country with a unique geographical landscape. There are over 6,000 islands and islets, of which only 227 are inhabited, while only 78 of them have more than 100 permanent inhabitants. One of the basic presumptions of a publicly funded health system – such as Greece's – is that all citizens have the same rights when it comes to the satisfaction of health needs. So, more than anything else, this means that access to the national health system's premises has to be guaranteed for all. However, as far as most of the small islands are isolated, there are only peripheral health facilities (something similar to a GP practice), usually manned by only one rural physician. In the case of an emergency, the physician may ask for a rescue helicopter to perform an evacuation. However, rescue helicopters may not be immediately available, since the officials of the National Centre for Immediate Care (EKAB) may be reluctant to send out a rescue helicopter if they are not sure that a real emergency is at hand. Occasionally, this may result in a late response, and even in a loss of a life which could have been saved; this reluctance could be explainable, since the number of unnecessary patient transfers is significantly high. Publicly funded medical evacuations by air constitute a limited resource which, in theory, has to be allocated according to certain medical and geographical criteria.

When inexperienced rural physicians fail to act as gatekeepers, the EKAB officials may attempt to take on this role. In this paper, we shall argue that this should never take place. A late response to a real emergency is certainly a worse outcome compared to an unnecessary airport transfer. The important question when allocating scarce resources has to do with the criteria that should take precedence in order to achieve as much justice as possible. Such criteria include medical benefit, cost-effectiveness, social considerations and desert-based principles. All these can weigh differently according to the circumstances. Any case at hand does not allow for lengthy discussions of these criteria, for two main reasons: first, there can be no certainty as to the medical condition of those demanding emergency transfer and, second, it is impossible to foresee how many demands will be placed, or when they will be placed. This element of uncertainty is inherent in the above-described situations, and it renders most of the commonly used criteria of resource allocation useless.

With the use of proper training and technological advances in the field of telemedicine, the whole system should probably function in a much more effective way within a few years; but, for the time being, unnecessary medical evacuations constitute a necessity.

THINKING OF HEALTH CARE AND JUSTICE: IS DERRIDA'S APPROACH TO JUSTICE HELPFUL?

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The question of allocation within health care systems is widely acknowledged as a question of justice. The distribution of scarce resources and priority setting is typically organised by rules or laws that need to be followed by professionals. These rules should then guarantee justice - for example just access to health care for all. This paper wants to follow a different idea of justice by taking Derrida's work *Force of Law. The Mystical Foundation of Authority* as a starting point. It is argued that by applying Derrida's approach to justice on the question of just allocation suggestions for new perspectives on the problem of allocation can arise. In his work Derrida describes two styles of deconstruction and applies them to the concept of justice. The first style can be called a genealogical style of deconstruction, it includes a movement to make historically grown restrictions of a concept visible. The second can be described as a movement to show the aporias within networks of concepts. Derrida shows in three aporias that the idea of justice as rules or laws needs to be mediated by the uniqueness of an experience or a decision.

This paper takes the deconstruction of justice and especially the three aporias as a starting point for an analysis of justice in health care systems. Following the argument in the first aporia justice is understood as the application of rules (of allocation). But the application needs to be more than rule following to be considered just: besides the dependency on rules justice – and just allocation – needs an independent free agent who is capable of more than compliance with formalities. The second aporia can be used to take a closer look at the problem of uniqueness of each case. Especially the difference between the classification of illnesses in general categories on the one hand side and the unique experience of a person being ill on the other hand side show that rules of allocation are made for one type of classification and generalisation. Different rationalities cannot be captured and the problem of the necessity to “apply” rules to unique cases and unique modes of description of the case need to be addressed. Interpreting justice as a maybe word (third aporia) and following the movement of deconstruction can keep up justice as an ongoing question of allocation by questioning the rules at the rim of the system. The role of experiences as a starting point of reflection can help to form a new understanding of the relationship between rules and rooms for decisions. The paper argues that following Derrida and understanding justice as a maybe word can bring up a dynamic factor to improve structures of allocation on the level of decision makers, formulation of cases as generalisations and decision latitudes.

VULNERABILITY OF MEDICAL INFRASTRUCTURES AND ROMA POPULATION.DO WE NEED A SPECIAL ETHICAL CODE FOR DEALING WITH GYPSY PATIENT?

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Within the European Union, the Roma minority is one of the largest minorities consisting of different groups, mostly nomadic with a variety of languages, traditions and skills. The visibility of such groups has increased in several EU countries due to the civil war in the Balkans and accession of Romania and Bulgaria. The presence of nomadic populations as gypsies are, raises many issues for sedentary populations from all over Europe, which invested a lot for having appropriate infrastructure and facilities. The access to such infrastructure is offered many times for free for Roma population but the sedentary population feels sometimes negatively discriminated because of the costs of that access. On the other hand the legislation of European Union is not all prepared to facilitate access to medical infrastructure of the nomadic population, who live in poor conditions and whose movements may be difficult to predict. Where is the balance between the cost of health care covered by sedentary population and the right to free access to health care for gypsies?

The existing codes of medical practice do not take into account the needs for medical care of nomadic populations and no country is doing any efforts to understand the needs of gypsies based on them requests. The article investigates the medical assistance of gypsies in Romania based on cases published in main newspapers. The objective of the article is to identify commonalities and divergences between opinions of the sedentary population and Roma population in relation with health care assistance provided in Romanian hospitals. The approach is based on the comparative analysis of opinions, recognising and interpreting underlying values.

For the purpose of the present analysis, four kinds of issues were distinguished: a) empirical ethical issues (when some issues are controversial largely because relevant empirical facts are in dispute); b)ethical conflicts between principles; c) interpretative ethical issues (different interpretations of the apparently same moral concepts and principles by static and nomadic populations); d) moral and legal issues (when we consider a certain practice to be morally acceptable or unacceptable).

Globalisation brings the promise of global diffusion of wealth but also entails the risk of deeper divisions. The Roma population is exactly at the border. Should we set up specific rules for dealing with gypsies as a specific case of nomadic population or simply consider them as an exception to the rule?

AUTISM, DECEPTION AND TRUTHFULNESS: A KANTIAN AND AN ETHICS OF CARE PERSPECTIVE

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Deception is a common phenomenon amongst normally intelligent human beings. Notwithstanding cultural differences, deception can be regarded as a universal trait of mankind. Lying, cheating, faking, fraud, malingering, dishonesty, secrecy and insincerity are instances of deceptive behaviors. Some of these behaviors seem to play a role in making social interactions run more smoothly. It is common knowledge that being honest not always is met with appreciation in everyday social encounters. Such honesty can be regarded as impolite or downright rude. Other deceptive behaviors, like fraud, appear to be always completely immoral. In general deception is regarded as immoral behavior, but some exceptions to the imperative 'do not deceive' are allowed.

Remarkably, deception is *not* a common phenomenon amongst normally intelligent human beings who are on the autism spectrum. They appear to be attractively morally innocent. Some of them report that their reluctance to lie has to do with the very intense emotions they experience, when they actually lie even if it concerns just a little white lie. It seems as if they have an above average moral conscientious objection against deception.

In this paper, experiences of deception and truthfulness written down in autistic autobiographies or so called autism narratives will be discussed. Different ethical theories shed different light on this matter. To show some insight into this matter of autism, deception and truthfulness, two rather different ethical approaches will be considered: a systemizing 'Kantian' and an empathizing 'ethics of care' perspective. High functioning persons on the autism spectrum are, generally speaking, strong systemizers and weak empathizers.

According to a systematizing Kantian view there is an absolute requirement of truthfulness. This seems near to the artists' intuitions. An ethics of care takes the perspective and the needs of the other person into regard. Autistic persons tend to have problems with empathizing this way, and it is difficult for them to override their "Kantian" morality to tell some white lie or deceive for the sake of the other person.

Both a Kantian approach to deception and truthfulness and an ethics of care approach will bring along problematic consequences for high functioning persons on the autism spectrum. Should non-autistic people adapt to a more Kantian morality or should we teach autistic people to tell small white lies when deemed appropriate from an ethics of care perspective?

COST-CONTAINMENT MEASURES IN EUROPE AND IN CHINA: ETHICAL ISSUES IN HEALTHCARE DISTRIBUTION AND PROFESSIONAL ETHOS

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Although it is well accepted that the cost of healthcare increases unbelievably fast and rationing becomes more and more necessary, there is little consensus on how to tame this beast of cost. Therefore, various cost-containment measures are used in practice; their effectiveness and ethical influences on patients, healthcare professionals and society are not fully examined.

The rising cost in healthcare and the cost-containment measures pending for assessment are not only salient problems for the Western world; they also challenge the healthcare systems in developing countries like China. However, due to the differences in healthcare financing, medical ethics and social context, the manifestation of problems and the coping strategies are not exactly the same for European countries and China. This article aims at delineating the peculiar healthcare system in China, highlighting the distinctiveness of its current cost-containment measures and comparing them with the ones used in Europe, and exploring the ethical issues of healthcare distribution and professional ethos around these circumstantial measures. Hopefully, the article will contribute to the understanding of the ethical implications of the cost-containment measures within social contexts.

CONFLICT OF INTERESTS IN SCIENCE: RECONFIGURING THE PROBLEM

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Conflict of interests (COI) issues in various dimensions of biomedicine became intensively scrutinized by policy makers and bioethicists in the recent decade, especially in the United States. For example, in 2009, the Institute of Medicine published its report that formulates major recommendations in order to avoid the problems of COI. Conflict of interests regulations are originated from the public arena, where public officials, government employees are seen as stewards of public interests. This ethical framework - based on the ethics stewardship - is highly problematic when applied to scientists. It is also problematic because it is grounded on role responsibility that is challenged by the current proliferation of different roles. The COI framework in science is also problematic because it has a sociologically simplistic conception of science as such. Thus, we have several reasons to be skeptical about the ethical adequacy of current perspectives of COI policies. I approach to identify the major problems that a new ethical framework should be responsive to in order to provide a better alternative in assessing and managing problems related to COI in contemporary biomedical sciences.

COGNITIVE AND MORAL ENHANCEMENTS AND HUMAN FREEDOM

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In the present paper I wish to explore the debate which has been going on between John Harris on the one hand and Ingmar Persson and Julian Savulescu on the other. In his fairly recent article entitled “Moral Enhancement and Freedom” Harris puts forward the claim that moral enhancement violates human freedom and, consequently, it cannot be accepted. In this way, he rejects the suggestion which Persson and Savulescu make in a number of recent articles, namely that we are in need of urgent moral enhancement by biomedical means, if we wish to control the tendency the contemporary man has to cause more harm than benefit to his fellow-men, a tendency which is further reinforced by the development of modern science and technology. Harris’ therefore strong point is that, even though cognitive enhancement by biomedical means does not affect human freedom, nevertheless moral biomedical enhancement violates it and as such it cannot be accepted.

I take this claim to be fairly strong and in the present paper I wish to question some aspects of it. First of all, I wish to examine the logical differences which exist between moral and cognitive enhancement, which allow us to defend the above claim. And secondly, because to a great extent the truth or falsity of the above claim depends upon the particular notion of freedom we hold, I want to consider the particular moral theory Harris espouses which enables him to support the above contention.

THE ETHICAL ROLE OF A PSYCHOLOGIST IN DILEMMAS OF PARENTAL CARE FOR SICK AND HEALTHY CHILDREN IN THE FAMILY

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A universal and fundamental challenge parents face is the distribution of their attention and resources among their children. This challenge is accentuated when one of the children requires more care and attention than the other siblings. Such differential demands are common when parents deal with a sick or very needy child. Some parents strive towards maintaining equality among all children, thus, inadvertently under-caring for the sick child. Others dedicate themselves to the sick child at the expense of a certain neglect of the healthy siblings, which may cause resentment among them. In fact, findings suggest that siblings of chronically ill and handicapped children are at risk for adjustment difficulties.

What is the role of a psychologist who is brought in to help families who have to solve the allocation of attention to their sick and healthy children? The answer to this question raises several ethical concerns. First and foremost, who is the “patient” in this context? Can the parents designate the person at the center

of attention? Second, it is not clear to what extent a psychologist should be directive when no obvious and direct harm is involved. Third, is there a way to say how a "Good Enough Parent" shares parental resources in such a complicated family. In other words - how does the psychologist tackle an apparent problem of relative justice in a typical situation of distributive family care?

FISHING FOR AN ETHIC OF WHAT MIGHT WORK: REFLECTIONS ON PUBLIC HEALTH INTERVENTIONS IN THE AREA OF ALCOHOL

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Alcohol misuse has become very common in our society. Drinking alcohol has instant effects that can increase the risk of many harmful health conditions, it can also create additional problems for underage drinkers. Alcohol use by young people is a major public health problem and although many people use alcohol responsibly, its misuse has become a severe and worsening public health problem in the UK.

There is a wealth of evidence to advise which alcohol policies and programmes are effective or ineffective to reduce the harm done by alcohol -what is particularly striking is that the policies which work are those that foster a supportive environment in which individuals are enabled to make healthy choices, although such evidence does not always translate into policy (Marmot, M.G. (2004) Evidence based policy or policy based evidence? *BMJ* 328: 906).

Sheron et al (2008) explain that according to the model constructed by the World Health Organisation, increasing taxes is the most efficient tool, followed by restrictions on advertising and, finally, by reducing the availability of alcohol (Sheron, N., Olsen, N. & Gilmore, I. (2008) *An evidence-based alcohol policy*. *Gut* ;57:1341-1344). The alcohol industry and the UK government have preferred the emphasis on education and information- based strategies. There is no evidence that these approaches reduce alcohol-related harm, however an evidence base is emerging in other public health areas and in the longer term these measures may come to be of some value. Information, advice and education campaigns may be significant in changing attitudes and in preparing public opinion for the introduction of effective measures, but appear unsuccessful when used alone.

However, there are some signs that public health campaigns are successful. Evidence shows they are more effective when combined with other measures, for example enforcement activity.

Room et al (2005) state evidence indicates that, although knowledge can be increased, and expressed attitudes may be changed, affecting drinking behaviour through school programmes is a challenging task. School-based attempts to influence individuals not to drink or to drink less have generally failed to display lasting effects (Room, R., Babor, T. & Rehm, J. (2005) *Alcohol and Public Health*. *The Lancet* 365: 519–30). Experience with public information campaigns is also largely negative. Unless

governments are willing to proceed with intensive counter-advertising campaigns, which the alcohol industry will take as a frontal attack, the most promising way forward for public campaigns in the alcohol field is rather in terms of building support for implementing proven prevention strategies.

The Government's failure to act is therefore not due to lack of evidence available, and could be viewed as a wish to cooperate with the alcohol industry. According to Room et al, (2005) in numerous places, the interests of the alcohol industry have effectively exercised a prohibition over policies, ensuring that the main emphasis is on unsuccessful approaches such as education.

This presentation will discuss which measures have been most effective in curbing alcohol misuse in Europe and the way forward for the U.K, how can we change the perceptions discussed and make public health campaigns a valuable tool in deterring alcohol misuse?

HEALTH CARE, GENES, AND JUSTICE: WHY IS THE DOUBLE HELIX SUCH A LOUSY LADDER?

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The promise of genomic medicine lies in individually personalized preventive and curative interventions based on one's genetic profile. The straightforward logic of direct, deep, and permanent genetic alteration is nearly irresistible to scientists, policymakers, and the public worldwide, especially in comparison to the challenge of reducing health disparities through social, environmental, and economic interventions. Who would not choose to develop and market a gene-targeting pill to eliminate type 2 diabetes, rather than attempt to make fresh produce and exercise opportunities widely available and affordable or eliminate fast-food advertising on television?

It is not a surprise, however, that the Human Genome Project is far from fulfilling even a small part of its promise. Most disease and disability is attributable to common complex disorders like type 2 diabetes. Science has identified few of the many genetic variants associated with such disorders, and is even farther from understanding gene-environment interactions. Thus we do not know very much about the genetic causes of and predispositions to the most prevalent life-limiting conditions of our time. But we do know that less-than-optimal living and working conditions can cause and contribute to these conditions.

We are bedazzled and distracted by genetics. Governments and industries invest in genomic research as funding for public health shrinks. No one would argue that the best way to deal with malaria, for example, is to identify the genes that contribute to susceptibility, rather than develop broadly effective medications and eradicate disease vectors. Why, then, do we seem to believe that those most disadvantaged by illness can climb the double helix to health?

One reason is the misplaced conviction that science is factual, straightforward, and indisputable. Gene-finding thus is a “value-free” scientific enterprise, more controllable than politically thorny attempts to reduce inequality of income, education, and opportunity. Another is the persistent human tendency to blame individual choices and actions instead of considering the social and cultural influences and policy-level decisions that shape and constrain individual behavior. In combination, these two myths seem to have revived belief in race as a biological rather than a social construct – partly because blaming individuals for their genetic makeup is curiously impersonal and therefore permissible, and partly because the potential profitability of genetic fixes remains tempting (whereas remedying poverty appears both difficult and thankless).

When Van Rensselaer Potter coined the term bioethics in 1970, he defined it as the integration of biology, ecology, medicine, and human values; yet bioethics soon narrowed its focus to medicine and health care. Our fascination with genetics is a direct consequence of that narrowing. So is our failure to address the messy questions arising from the health effects of social and political institutions and the relationship between human and non-human life on earth. Science cannot improve the health of individuals by manipulating human genes in a vacuum; it is necessary to address how we live in the world. For the same reasons, bioethics can no longer avoid addressing the root causes of health disparities around the globe.

EVIDENCE-BASED BUT ETHICS-FREE CLINICAL PRACTICE GUIDELINES? FINDINGS OF A SYSTEMATIC REVIEW OF ETHICAL CONTENT IN DEMENTIA AND CHRONIC KIDNEY DISEASE GUIDELINES

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Background: Since 10 to 20 years clinical practice guidelines (CPG) aim to improve standards of clinical competence by referring explicitly to evidence-based information on benefits and harms. While this development is laudable also from an ethical perspective CPGs and their development manuals fail, however, in addressing disease specific ethical issues (DSEI) that are deeply intertwined with the concepts of clinical competence and professionalism.

Objectives: To assess the extent of how a representative sample of CPGs for dementia and chronic kidney disease cover recommendations of how to deal with DSEI.

Methods: First, a systematic review of ethics literature on dementia and chronic kidney disease was performed. The included literature was analyzed qualitatively in order to develop a theoretically saturated set of DSEI (see abstract of Schmidhuber M et al.). Second, a systematic review of CPGs on dementia and chronic kidney disease was performed. Finally, we assessed the representation of DSEI in all included CPGs using the aforementioned DSEI-sets as a framework.

Results: The systematic review together with qualitative analysis finally produced 26 DSEI for dementia and 18 DSEI for chronic kidney disease. All DSEI could be grouped under 7 main categories (indication, patient information, patient decision making competence, proxy decision making, social and context related aspects, clinical conduct, evaluation). We present qualitative and quantitative differences in how comprehensive current CPGs represent those DSEI. Interim analyses show a rather poor representation of those DSEI in CPGs of dementia and chronic kidney disease. The analysis will be finalized in May 2011. We also discuss further steps necessary for the systematic integration of DSEI in CPGs.

Discussion: Concerning the rationale given above we conclude that DSEI should be better represented in CPGs. Methods for a systematic and transparent integration of DSEI in CPG should be addressed in CPG development manuals.

PRACTICES OF JUSTICE AND SOCIAL INEQUALITY – FIELD STUDIES IN GERMANY AND NORWAY

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Background: Two field studies in clinical ethics from Germany and Norway revealed practices of injustice with regard to the social status of the patient and his family, his or her status of health and possibility of speaking up for his or her interest (Kohlen 2009; Halvorsen 2009). It was also elucidated that professional actors felt struggled being in a position of setting priorities due to economic constraints and lack of personnel, a situation that contributed to increase coincident practices, as well as injustice and inequality. The context of the German study was clinical ethical committees. The focus was on the ethical issues raised and the priorities and exclusions that were made. The Norwegian study was performed in an ICU context and centered on the ethical issues raised with regard to bedside priorities.

The findings provoked a discussion on understanding injustice not as an abstract ideal, but as a concrete practice in the every-day world of physicians and nurses. The findings shed light on the actors' need of reaching out for moral arguments in preventing just caring practices.

Objective: The objective of this paper is to elucidate the practices of injustice more clearly within the two different contexts. Further it aims to discuss perspectives of justice and care, and reflect on how physicians and nurses in caring practices can argue for just practices of care as a concrete value in their everyday work.

Methods: In both countries the research took place in three hospitals over two years. Field research that combined participant observation and interviews were used in both projects. The data was structured along content analysis and interpreted hermeneutically. The empirical data from both studies will ground the theoretical discussions in this paper.

Conclusion: The studies from Germany and Norway revealed implicit priorities that lead to unjust medical treatment and nursing care, mostly affecting medical and nursing care of patients and their families with apparently lower social status and a vulnerable network. The principle of justice is a core value in health care in Germany, as well as in Norway and is based on international human rights. Fundamental in the principle of justice is the particular moral responsibility to protect who need it the most. Inequality based on moral judgment of social or economical status, or other not ethical relevant reasons, are not an acceptable value in health care practices.

COST CONSIDERATIONS IN PANCREATIC CANCER TREATMENT DECISIONS – RESULTS FROM A QUALITATIVE INTERVIEW STUDY WITH STAKEHOLDERS IN HEALTHCARE IN GERMANY

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Medical progress and demographic changes have led to increasing financial pressure in modern health care systems. One possible reaction to this problem is (increased) rationing of medical services. However, rationing encounters much political and ethical resistance. This seems especially true in Germany, which has a long tradition of universal coverage of all medically necessary services regardless of their cost-effectiveness. Recent debates indicate that various stakeholders in Germany start to rethink whether cost considerations do or should play a role in treatment decisions. One area of special focus is cancer treatment which often is very cost-intensive but not always very effective. A case in point is pancreatic cancer, a very aggressive disease with poor prognosis.

Against this background we have conducted a qualitative interview study with various stakeholders in health care in Germany, funded by the German Federal Ministry of Education and Research (BMBF). The goal of this study was to examine the experiences and attitudes of physicians, members of the medical review board of the statutory health insurance funds (Medizinischer Dienst der Krankenkassen, MDK), health politicians (members of the parliamentary committee on health of the German Federal Parliament) and leading officials in the health care sector regarding cost consideration in treatment decisions with particular reference to the example of pancreatic cancer treatment.

We conducted semi-structured, guideline-based interviews and analysed them using grounded theory. Our main focus was on the questions (1) whether the respondents could accept rationing in pancreatic cancer treatment due to cost considerations from their professional points of view; (2) who, in their view, should be authorized to decide on the provision or restriction of medical services; and (3) on which criteria such decisions should be based. In the paper, central results of our interviews will be presented. So far, most

empirical studies investigated general opinions on health care rationing in physicians. We add a broader picture of various stakeholders in health care in Germany with a special focus on cancer treatment.

CLINICAL RESEARCH IN RUSSIA: PROTECTION OF THE INTERESTS OF PARTICIPANTS (*)

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The issue of patient's protection in Russia is one of the most unfortunate ones, as a consequence of the unethical activity of pharmaceutical companies. Russian legislation does not have any mechanisms to protect those individuals taking part in clinical research and having suffered from side effects of medicinal preparations. There is no legal regulation of clinical research institute studying already authorized preparations.

There are no information about side effects of medicinal preparations in our country. It is impossible to suppose and trace what are negative effects after the use of such preparation. This situation is also complicated by inertness of doctors in respect to this problem.

According to ethics, doctors must inform patients about side effects, but such procedure, stamping of documents, proving are extra amounts of work for them. It is also difficult to prove display of side effects as blood counts, saying nothing of other tests, are not taken from those who dies a natural death.

The problem of clinical research was shown in full amount by tragic events in Volgograd and Tomsk. According to the information from public prosecutor's office illegal tests some vaccines were carried out in departmental hospital in Volgograd to the order of Belgian company "G". Side effects were found at some children.

It was stated during inspection that about a hundred children of 1 – 2 years were involved in the tests of medicinal preparations without the knowledge of their parents. This testing was approved by the Committee on ethic at the Federal for quality control of remedies, but it is evident that the decision of the Committee was illegal as the law "On the remedies" orders the possibility to carry out research only in state or municipal hospitals, but meanwhile, this tests was carried out in the hospital belonging to company "R".

Such scandalous examples, with children taking part in it, lead to great public resonance and make Russians think about conscientiousness of medical workers and honesty of officials. Patient's confidence in the doctor and the authorities is a corner-stone of civilized health services system.

At last, pharmaceutical companies create funds to support scientists who get salary from them. But the trouble is that these scientists are enlisted then as independent experts to make conclusions on side and negative effects of preparations.

The way out of such legislative situation may consist of the following measures: 1) the procedure of clinical research must be clearly defined; 2) there should be created independent body, institute of independent examination of medicinal preparations and their side effects; 3) it's necessary to find out exactly the death-rate as a result of side effects in Russia.

(*) This research is prepared within the context of the federal special-purpose programme «Scientific and pedagogical personnel of [innovative](#) Russia» (2009-2013).

ON THE CONTINUED NEED FOR A NEW (BIO)MEDICAL MODEL

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In 1977, George Engel suggested that there was a need for a new medical model. He complained that the dominant model took an inappropriately reductionist stance. There was little or no scope for any consideration of the psychological, social or behavioural aspects of being unwell. To facilitate a move away from this situation and inspired by the work of Ludwig von Bertalanffy and his General Systems Theory, Engel proposed what he called the Biopsychosocial model (BPS). This attempted to represent a hierarchy of interacting levels comprising and relating to the well-being of the individual.

Contemporaneous with the genesis of the BPS was the emergence of the debate about the definitions of disease and health – a debate which is still on-going. Although the work of Christopher Boorse has sought to distil a definition of disease from the way in which the word is used – and might, therefore, be said to be a depiction of the mental framework or model within which this usage occurs – the debate cannot be said to have drawn extensively on the BPS or any other such model. It may be that part of the reason the debate has not reached a conclusion or a greater level of agreement is due to the very absence of such models. Thus, the debate may well be assisted by the development of a viable model which can accommodate the diverse aspects of individual suffering.

This paper will present the outline of such a model with the intention that it may prove useful in the aforementioned debate. This model also takes a lead from systems thinking but does so founded on the tenets of evolutionary biology. However, instead of emphasising gene or population level phenomena or, indeed, reproductive success – as is commonly the case in modern biology – it is the survival and quality of life of the individual which is emphasised. Instead of using a single linear hierarchy to represent the individual, different orthogonal axes are used to represent concurrent aspects of the state of the individual and that individual's ability to interact with the world. A basic two-dimensional version of the model uses axes to represent an individual's level of physical disorder and experiential disturbance while a three-dimensional version adds an axis which represents the level of behavioural constraint experienced by the

individual. Features represented by each axis have a direct bearing on the survival chances of the individual and it is within this framework that the concepts of disease and health may be further explored. The model does not use axes representing what might be considered 'typical' biological or medical parameters nor are the axes used as might be expected. Nevertheless, those aspects of the individual which Engel considered important are included, albeit in a different (non-hierarchical) way and using different terminology.

WHAT DO WE REALLY KNOW ABOUT THE DELIBERATE USE OF PLACEBOS IN CLINICAL PRACTICE?

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Deliberate use of placebos is usually considered unethical outside the context of clinical trials. It is often claimed, however, that placebos are frequently used in clinical practice. A few studies from the past two decades seem to suggest this and they are referred to as evidence of such use. A closer look at three such studies demonstrated that the concept of the placebo was understood in many different ways, and that definite conclusions of the prevalence of placebo use could not be made. My aim now is to find all studies that have examined placebo use in clinical practice and explore what is really known about the topic. The results of this analysis are presented at the conference.

CONSENT TO GOVERNANCE AND TRUSTWORTHY INSTITUTIONS – NEW CHALLENGES TO RECS?

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Biomedical research is considered to be important and necessary because this is the way how medicine can evolve, the way to new knowledge, new methods and better treatment. The benefits of the research can be seen on different levels: from personal to social, from direct to indirect. There are many requirements that should be fulfilled in order to make human biomedical research ethical. One of these requirements is independent ethical review, which is considered to be an important safeguard.

After a decade has passed the mapping of human genome which was an event that paved way for new developments in the field of biomedicine and called for changes in the governing ethical frameworks (e.g. focusing to common good instead of autonomy) we can say that broad consent is considered to be an accepted solution for research involving biobanks and databases. This means that the consent is given for using the data in research for future purposes, not for each specific use.

Jane Kaye argues that by giving broad consent an individual is effectively giving a broad consent to the inclusion in a biobank but then gives 'consent to governance' – or consent for others to decide upon their behalf (Kaye 2009: 206). In an area when individuals have no meaningful control over how their data is used, the only way forward has been seen as to establish independent governing bodies. These institutions will be authorized to make decisions on behalf of the persons whose data will be used in research. In order to preserve trust, this solution requires democratic public sphere. It is important that the general public agrees and accepts the role the institutions will serve. This means that the general public should be involved into decision making process about necessary protection, that there should be informed public debate. Also there should be technical, procedural and control mechanisms. Also the institutions should be understood in broad sense, not only as RECs. It is important to realize that autonomy can appear at another level, e.g. participating in public discussion about what kind of measures should be taken to assure trustworthiness of institutions.

In my presentation I'm going to find out whether it would be possible to put there principles – consent to governance and trustworthy institutions – into practice, what requirements for changing current approaches this will bring and whether this will be the way forward or not

PRIORITY SETTING IN THE GERMAN STATUTORY HEALTH INSURANCE SYSTEM

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Background: The German statutory health insurance system covers over 90% of the population. Membership in one of the sickness funds is mandatory up to a certain income threshold. Contribution rates are calculated as a certain percentage of the gross income and are independent of age and health status. Depend family members are covered without any additional premiums. Above the income threshold, people can opt out of the public system and purchase private health insurance. The statutory health care system provides a rather generous, uniform benefit package that includes hospital care, ambulatory care and pharmaceutical services. All services are covered that are necessary, adequate and efficient to treat or prevent diseases. There are only minor exclusion (e.g. non-prescription drugs) and moderate copayments. The federal joint commission (Gemeinsamer Bundesausschuss – G-BA) decides about the benefit package.

Priority setting in the German health care system: There is increasing empirical evidence that there is implicit and usually covert rationing in the German health care system. Still, German health politicians resist to talk openly about the fair and efficient allocation in the statutory health care system and – as a consequence – there are no structures or procedures in the German system for explicit priority setting. In

2000 and 2007, the central ethics committee of the Federal Physician Association (Bundesärztekammer – BÄK) published two position papers on priorities in health care, urging German politicians and decision makers in the health care system to start an open public discourse on the appropriate methods and criteria of priority setting – based on the assumption that priority setting is inevitable in the German system under the conditions of an aging society and increasing cost pressures due to biomedical innovations and it should be done explicitly. Unfortunately, these papers had a very limited impact within the system. Interestingly, in 2007 a federal law (Gesetz zur Stärkung des Wettbewerbs in der gesetzlichen Krankenversicherung – GKV-WVG) required the Institute for Quality and Efficiency in the Health Care System (IQWiG) to assess benefits and costs of medical interventions, especially pharmaceuticals. There was a vigorous debate about the appropriate methodology and the IQWiG chose – following the advice of an international expert panel – the efficiency frontier as methodology. However, in 2010, a new law came into effect that again changed the procedure (Arzneimittelmarkt-Neuordnungsgesetz – AMNOG): After an early benefit assessment, the sickness funds negotiate prices with the pharmaceutical industry. It is still open, what the effect the AMNOG will be.

Conclusion: Given the demographic change and increasing cost pressure due to medical innovations, the public German health care system has to set coverage limits. So far, the allocation is dominated by implicit, hidden rationing. From an ethical and health policy perspective, Germany should start an open dialogue in politics and in society in general about methods and criteria of priority setting.

ARE BANS ON KIDNEY SALES UNJUSTIFIABLY PATERNALISTIC?

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Two powerful arguments are often put forward against the near universal ban on kidney sales. First, it is argued that allowing such sales would increase the amount of kidneys available for transplant, potentially saving lives of patients on waiting lists. Second, it is claimed that prohibiting kidney sales is unjustifiably paternalistic, that it denies would-be vendors the opportunity to do what they think is best with their own bodies. While the first argument is more widely debated, it is also weaker in the sense that it relies on challengeable empirical assumptions.

This paper examines the second, more principled argument. It questions the assumption that anti-paternalists should oppose bans on kidney sales. Drawing on the well-known distinction between soft paternalism (which anti-paternalists accept) and hard paternalism (which they repudiate), I argue that such bans are best understood as being of the former kind. More precisely, they belong to an often-overlooked category of interventions that Frank Miller and Alan Wertheimer call “group soft paternalism”. Bans on

kidney sales restrict the freedom of autonomous individuals. However, that restriction is not justified by reference to these individuals' own good (hard paternalism), but as an unavoidable side effect of protecting other, non-autonomous individuals from making harmful choices (soft paternalism).

The group soft paternalistic case for prohibiting kidney sales rests on three conditions: that sales are potentially harmful to vendors, that many vendors would not choose to sell autonomously, and that distinguishing between autonomous and non-autonomous vendors and interfering only with the non-autonomous ones is unfeasible. I provide reasons for thinking that these conditions will often hold.

A PARADIGM SHIFT IN PUBLIC HEALTH? EXPLORING PHILOSOPHICAL AND ETHICAL IMPLICATIONS

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Public health has epidemiology as one of its major pillars. Within epidemiology the focus has moved from the sanitary statistics and infectious diseases to chronic diseases of complex etiology. Because of the diversity of diseases and risk factors, an essentially empirical, statistical approach was adopted, leading to a multitude of mostly 'proximate' risk factors (McMichael, 1999). This has resulted in many scientific insights and angles of actions for health prevention and policy.

However, there are problems. The growing occupation with individual risk factors largely eclipses ideas of social causation of disease. Thus, individuals at risk can be determined, but patterns of disease in a population cannot be explained. And even after decades of 'risk factorology' only a third of the contributors to e.g. prostate cancer is accounted for, with similar situations for CHD, diabetes and stroke (McKinlay, 2000). Also, the potential of this approach for improving public health is declining. The easy-to-reach 'risk fruit' seems to be harvested; new risks for health are continuously being discovered but their scale and public health relevance are often minute. This results in epidemiological confusion amongst both public and prevention professionals and reduces trust in science and government. The current approach in epidemiology and public health also has considerable ethical impact: the often implicit assumption that health is a private rather than a public matter has contributed to a moralisation of health and disease, with 'blaming the victim' and diminished public responsibility as some of its consequences. And since health promotion increasingly focuses on individual behavioral changes -proven to be more difficult than hoped for- health inequalities persist or even increase.

In short, epidemiology and thus public health are held 'prisoner by the proximate' (McMichael, 1999). There appears need for a new approach, a new paradigm for epidemiology and public health of the 21st century. Moving beyond risk factorology to a more 'ecological' approach in which complexity is not merely reduced to risk factors, humans can be seen as systems consisting of other systems while at the

same time being part of larger ones, like ‘Chinese boxes’ (Susser&Susser, 1996). This may lead to a better understanding of how disease and health finally come about and how they are distributed in a population. Also, health and disease at an individual level can be seen as the embodiment of power structures and differences (Krieger, 2008) through various pathways to health and disease (Fleischer, 2006).

This session attempts to explore where such paradigm developments may lead us. What does it mean to acknowledge complexity in public health thinking? What different research questions and alternative leverage points for policy and prevention may be expected? Also, regarding philosophical and ethical questions: what does this it mean for the way we conceive of health and disease. Does it solve ‘blaming the victim? What will such a scientific paradigm shift mean for the societal distribution of responsibilities regarding health and disease and their causation and distribution?

INFORMED CONSENT: WHAT CONSTITUTES ‘INFORMED’? A MORAL THEORY APPROACH.

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The notion of informed consent is one that has raised its head once again recently over the ‘information leaflet’ issued by the UK NHS Breast Screening programme in 2010 (Department of Health, NHS Cancer Screening Programme *NHS breast screening* December 2010), with critics saying that it is a ‘disgrace ‘ and that it is ‘unbalanced’ and that the ‘major harms of screening...are not clearly explained.’ (Mayor, Susan (2011) NHS breast screening leaflet glosses over harms, say critics *BMJ* 342 12 1 January). This leaflet replaced one that was issued by the Department of Health in 2006 and was itself heavily criticised, and hence rewritten by an expert in informed consent.

Leaving aside issues regarding screening programmes, this paper will focus on the notion of ‘informed consent’. It is a term that has gained ground over recent years. But how informed is informed? Even taking Mason &McSmith’s subjective view of informed consent that: ‘what would that particular patient have considered to be adequate information?’ (Mason, JK, Laurie, GT (2006) *Mason and McSmith’s Law and Medical Ethics* 7th ed Oxford: OUP), where does that leave us when deciding how much or what kind of information should be required for patients, or in other words , what is ‘adequate’? Could utilising a moral theory, that of Alan Gewirth (Gewirth, Alan (1978) *Reason & Morality* Chicago: University of Chicago Press), be of assistance in clarifying the necessary content for informed consent through the prevention of harm to agency? This paper will explore such an approach and ask whether it is of assistance in elucidating the necessary content of ‘informed’ consent, and furthermore, is the definition of such ‘necessary’ content a possible task or a perfectionist’s (philosopher’s) fairy tale?

HUMAN DIGNITY AFTER KANT – A SUSTAINABLE AND RELATIONAL MORAL IDEA?

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“HUMAN DIGNITY IS NOT SOMETHING THAT YOU HAVE ONCE AND FOR ALL, IT IS SOMETHING THAT HAS TO BE SUSTAINED.” The quote above is the answer from an interviewee to the question: “What thoughts and reflections come to mind when you hear the concept ‘human dignity’?” In interviews with doctors and chaplains about ethics in the beginning of life and the end of life, one of the interviewees expressed the thought of human dignity as a value that has to be sustained. It was clear that this is done through showing respect for the patient’s integrity and helping the patient to make autonomous decisions. Sustaining human dignity also involved that the individual should not have to endure extreme suffering. Human dignity was not understood as a value that an individual has because she is a human being and *therefore* others should show her respect. Rather it was understood as a value that is sustained *through* the repeated actions, for example of respect, towards others. The consequence of this thought is that human dignity is understood as a relational ethical concept because it is created in the relationships between people.

Immanuel Kant’s philosophy about human dignity has had an enormous impact on how the concept has been understood in western philosophy and it has influenced, for example, ethical guidelines for medical care. Characteristic for Kant’s argument concerning human dignity is that a human being is rational and because of her rationality she is not to be treated only merely as a means but always at the same time as an end, as formulated in the categorical imperative. In Kant’s philosophy there is no relational aspect involved; it is a value that all individuals have, regardless of what recognition they have of their own dignity and regardless of what recognition others have of it.

The two different understandings of human dignity raise new questions about how to understand the concept and what consequences this could have in medical ethics and medical care. What can a relational understanding add to a discussion about human dignity and can the concept of human dignity after Kant instead become a sustainable and relational moral idea?

ACCEPTANCE OF RATIONING HEALTH CARE BY THE GERMAN POPULATION – AN ETHICAL DISCUSSION OF AN EMPIRICAL STUDY

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An empirical survey on the attitudes of the German population about health care rationing has been performed in autumn 2008. 1,500 German citizens (representative population section, age: 18-79 years) have answered a questionnaire. The investigation had been organized by the editors of the “Bertelsmann Gesundheitsmonitor”.

The survey has investigated the attitudes of the German population towards rationing in health care, especially towards a system of basic health insurance and private additional insurance and towards prioritisation. Furthermore, it has researched in how far the German population wants to participate in decision-making about public health and to which institutions the population wants to delegate decisions about rationing.

The data have been analyzed by descriptive statistics. Logistic regression models have been used for investigating the influences of socio-economic and health-related factors.

The main results of the study are: Rationing is not accepted by the vast majority of the Germans. There is a nearly unanimous rejection of the limitation of necessary medical benefits because of high age or chronic or untreatable diseases. More than two thirds of the persons interviewed favor an all-inclusive public health insurance over a system of basic health insurance and private additional insurance. Priority is given first for benefits for children, second for benefits for as many people as possible. The gross majority demands for a stronger influence of the population on savings in the health care systems. Nevertheless, the majority agrees with the current practice of delegating concrete decisions about rationing benefits to the treating physicians. Asked for prioritization, the people gave the lowest values for cancer therapy for smokers and for the treatment of schizophrenia; this indicates first a strong belief in responsibility for at least certain diseases and second a devaluation of either psychiatry or psychiatric patients.

Since the gross majority of the German population objects to the (further) rationing of health care benefits, future reforms of the health care system should firstly exploit further potentials of rationalization and secondly improve the income account of the insurances. If rationing would be really unavoidable, all rationing procedures should be transparent, not dependent on rigid age limits, and flexibly applicable. If the population should be involved in the development of a prioritisation list, then it has to be made sure that medical benefits, which are indispensable for ethical, medical or economic reasons, cannot be challenged.

PLASTICITY OF THE BRAIN AND THE DANGER OF ASKING TOO MUCH

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Recently, there is much scientific and public excitement about the brain's capacity to adapt to experiences with changes in neuronal activity, structure, and function by producing new cells, new connections, or modulating established connections. Plasticity is ubiquitous: Any experience in everyday life, and each purposeful intervention leave its footprint in the brain. Studies on neuronal plasticity shed light on questions ranging from effects of development, learning, pathological states to effects of psychoactive drugs and cortical stimulation. Widespread importation of scientific thoughts into popular culture suggests that we discover how to determine the way our brain determines us.

Besides general scepticism regarding the neuroreductionist tendencies that are proliferating in popular media and the common understanding of our way of being, feeling, and behaving, the implications of these neuroscientific findings for the healthcare system and its pursuit of the individual's and society's best demand scrutiny: Research on plasticity has tremendous clinical potential, e.g. with respect to neurorehabilitation. Doubtlessly, this potential needs to be deployed as far as possible to improve patient's recovery and quality of life.

But there is more to the application of this research: Knowledge about alterability apparently requires rethinking of what we are responsible for. This holds for patients, physicians, but also for healthy individuals. If alterability is a central phenomenon, everyone might be able and obligated to exert oneself in the improvement of brain behaviour. If we learn more how we could influence our brain by manifold means, it might be asked from everyone to do so in a particular way. It might be required to ensure one's own health and well-being by benefitting from science's discoveries. However, being encouraged to understand oneself as biomedical subject that is continuously open to directed change puts a great burden on individuals. One might demand from individuals to train and influence their brains in specific ways.

Communication of the potential to work on one's brain's processing and the plethora of options opened to everyone can impact private, working, and public life. It might lead to pressures that are harmful for individuals and society at large. While respecting autonomy as highly valuable, one needs to recognize that the *right* to decide autonomously is not the same as the *competence* to do so.

Patients and healthy people might not be able to handle the options and demands put on them by focussing on plasticity. They could be harmed by overstrain. As society incites individual responsibility and pursuit of self-fulfilment with good intents it could overwhelm the individual. Thus, discussing plasticity and the growing option-space must be coupled with a sensitive analysis of how people can deal with the potential. Grounds for caution are not only necessary concerning overhyping potential

neuroscientific applications, but also concerning the initially-expected beneficial effects that might turn out to be harmful.

Effective social appraisal of the discussion around plasticity in clinical and non-clinical contexts alike requires a humble and sensitive approach to serve the individual's and society's best.

IDENTIFICATION AND CLASSIFICATION OF DISEASES: FUNDAMENTAL PROBLEMS IN MEDICAL ONTOLOGY AND EPISTEMOLOGY

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In this paper I focus on some problems surrounding the identification and classification of diseases. After a brief survey of the history of disease classification I concentrate on two contemporary enterprises, viz. the traditional International Classification of Diseases and Causes of Death (ICD) and the Systematized Nomenclature of Human and Veterinary Medicine (SNOMED). The two systems are very different and were originally designed for different purposes. The SNOMED system is much more elaborate and sophisticated and one could argue that it ought to replace the ICD altogether. I discuss in the paper arguments for and against such a replacement. I will particularly focus on the idea that there is an ultimate essential site of every disease which should determine its classification.

REMOTE MONITORING OR CLOSE ENCOUNTERS? ON PRIORITY-SETTING IN HOME-BASED HEALTH CARE

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During the last few years, we have seen an avalanche of new technologies for personal health monitoring of patients and elderly people in their homes. A driving force behind this development is the demographic time-bomb, i.e., the substantial demographic shift that is underway in terms of a rapidly growing proportion of elderly in society. Health care decision-makers argue that in order to provide good care to these elderly people it will be increasingly necessary to provide this care at home through personal health monitoring rather than at institutions. This is necessary for reasons of cost and efficiency. Critics maintain, on the other hand, that we must never forget the needs of the patients and the elderly. They may not want a technological invasion of their homes leading to reduced personal contacts with care providers. In this paper, I discuss issues of priority-setting raised by this new development. It appears that four clusters of values are relevant: (1) independence and privacy, (2) health security and safety, (3) social contact with relatives and care providers, and (4) reasonable costs and efficiency. I argue that we should

be aware of the variety of preferences of individual care recipients. To some patients and elderly people the independent living made possible by remote monitoring is more important than social contact with care providers, to others social contact is more valuable than independence. We should take the preferences of this latter category seriously. I therefore support an approach that is more sensitive to individual differences than the approach of more generally replacing close encounters by remote monitoring.

ROLE OBLIGATIONS AND MODERATE PARTIALITY IN HEALTH CARE

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Some ethical theories argue for the significance of relational responsibilities and a moderate partiality as a part of their central normative orientation. Moderate partiality means that moral choices always have to account for the web of relationships, the relational networks and responsibilities that is an essential part of particular moral circumstances. What this means as a basis for priorities and distributive justice, however, is notoriously unclear. This paper will discuss the conditions for health care professionals to act on the basis of particular responsibilities to their patients. We will argue that priorities within clinical health care might be partial in three ways: 1) There might be exceptional circumstances which allows for giving priority to one patient before another, based upon other considerations than need for medical care. 2) The integrity of the patient and a health care worker might be interdependently connected. 3) Even if impartiality is essential to health care priorities, the institutional basis of health care must always give ample space for an ethically qualified individual and personal care and concern for patients. Even if hard priorities might be necessary, the conditions of institutional health care should always seek to create the conditions for nurses and doctors to do proper care.

ETHICS AND DISASTER RESEARCH

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Disasters are characterised by massive suffering, casualties and death. Infrastructure and regulatory mechanisms may be devastated. Difficult decisions about how to respond must be made. Yet for many questions, little or no validated information is available to point to what works, or what works best. An ethical mandate exists to conduct disaster research to learn how best to take care of people and how best to use the available limited resources.

Such research must comply with established ethical principles. However, disaster settings raise a number of particular ethical questions. The rapid response required by disasters raises challenges for a slow and deliberate ethical review process. The trauma and destruction visited upon survivors raises questions about their degree of vulnerability. The dual role of researchers as doctors or other responders raises questions of conflict of interest. Some question the ethics of using any resources for research when people are dying and infrastructure is falling apart.

This paper will discuss these issues and make a number of proposals. Such guidelines will be presented to engage participants in further dialogue as part of an on-going project on Disaster Bioethics (<http://DisasterBioethics.com>).

WHO'S USING ENHANCERS ANYWAY? RESULTS OF TWO EMPIRICAL STUDIES AMONG SWISS PHYSICIANS AND STUDENTS

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With the help of empirical studies, we will reveal the use of cognitive neuro-enhancement products (NEP) among students of the University of Zurich as well as the importance and handling of NEP by Swiss physicians. Cognitive Enhancement stands for the non-medical use of drugs to increase concentration or alertness. Drugs which are most commonly used for this purpose are at present Ritalin and Adderall. Another psychostimulant belonging to the well-known NEP is Modafinil.

Ritalin and Adderall were invented to treat attention deficit hyperactivity disorder (ADHD) whereas Modafinil was generated to treat fatigue caused by narcolepsy, sleep apnoea and shift-work sleep disorder. Reviews about different studies revealed that all three drugs do increase concentration, alertness and/or reaction time in healthy probands. Until now, four surveys have been done in the last 10 years to investigate the non-medical use of such NEP. One survey was done in the US among 10'904 college students concerning the non-medical use of Ritalin, Adderall or Dexedrine. Another survey was accomplished by the journal Nature among 1400 Nature readers from 60 countries concerning Ritalin, Modafinil or beta blockers. A third survey among 3000 employees in Germany between the age of 20 and 50 years was conducted by the "Deutsche Angestellten-Krankenkasse" (DAK). The latest survey was carried out among 1035 pupils and 512 University students in Germany in 2010. The lifetime prevalence of non-medical prescription stimulant use was 6.9% for the almost 11'000 students in the USA and 20% for the 1400 Nature readers. In Germany, the life time prevalence was 5% for the 3000 employees, 1.55% for the 1035 pupils and 0.78% for the 512 students.

The online survey among students of the University of Zurich will ask about the use of NEP and reasons therefore. The questions are formulated in a way to allow comparison with the data of the survey among

students in the US and in Germany. Further questions will reveal the attitude of the students towards the use of NEP as well as towards the main ethical implications of NEP which were arisen in literature. To reveal the importance and handling of NEP by Swiss physicians, qualitative interviews were held with four psychiatrists and four general practitioners. On the basis of the given question, a questionnaire including six case studies was constructed. The goal of the questionnaire is to reveal the knowledge of physicians about NEP as well as their attitude and handling of NEP. The questionnaire will be sent to 1600 physicians in Switzerland (German and French speaking part) to receive at least 480 complete questionnaires when calculating with a 30% rate of return. We would like to present the data of the qualitative interviews with psychiatrists and general practitioners and the preliminary data of the online survey as well as of the survey among Swiss physicians.

THE NEBULOUS RELATION OF THERAPEUTIC ENHANCEMENT TO EGO ENHANCEMENT

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Human enhancement (HET) is a highly contested issue. In this paper I will discuss the aspects of this practice which cause disputes and debates. I will claim, first, that the legitimization of the research in medicine and in technology the results of which are employed in HET is found originally in the therapeutic role of such substances or devices. The extension of the use of such substances for non-therapeutic purposes such as the satisfaction of personal ambitions and desires, the fulfillment of individual aspirations, the realization or the alteration of one's self-image is, at best, problematic since it is illicit. The case of Ritalin, a drug prescribed legally to treat ADHD, which, however, can be obtained also illegally -either without a prescription or with a fake one- to function as a "universal performance enhancer is paradigmatic. In addition to the conceptual, the legal, the social, the economic and the ethical difficulties in justifying the use of an illegal "universal performance enhancer", there is the problem of clearly defining the purpose of its use. The promised "happiness" to be found at the end of the tunnel hardly lends itself to a clear definition. The same obscurity and nebulosity is true of another *terminus ad quem* of enhancement practices, namely, intelligence.

Another set of issues concerning HET has to do with "who pays and why, and who benefits and why" from the research the results of which are also used in various enhancement practices. Research funded by governments is research paid by everybody and this is done in the name of a value shared by all, namely health. The question is, can everybody afford the end-products of such research? The answer is clearly, no. What about the various "enhancements" which are not temporary, they are permanent, irreversible

and one's children can inherit them. Such "enhancements", however, may lead to the appearance of a caste of the "enhanced" in a society, a development which may have unforeseeable consequences.

HET is sometimes presented as a panacea of all social ills. An enhanced society would be problem-free. The question, at this point, would be which society. Does this mean every society on the planet? This is hardly possible. Grave problems arise from such declarations. These problems are laden with ideological assumptions, religious affiliations, anthropological biases, economic considerations and, of course, ethical dead-ends.

Despite the danger of the medicalisation of all modifications of the human body -and of the mind- it seems safer to rely on protocols deriving from the scrutiny of specific cases and open to the criticism of all concerned rather than on the whims of people's egos.

DO MARKET MODELS IN THE HEALTH CARE SYSTEM LEAD TO MORAL MUTENESS?

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Professionals are granted permission to perform actions that people in general are not allowed to do. Therefore, critical reflection on professional activities is important. Even if an inherent 'role morality' addresses many of the moral issues that arise, there is still a professional/client asymmetry that must be bridged somehow. Relying on trust is not sufficient anymore. With the advent of new technologies, altered public expectations, and novel incentive schemes a broader discussion about the values of both the institution and its professions seems necessary. Clients need to know what to expect, and professionals must know how to be good within the institutional framework. Such *moral* competence requires moral discourse. Here, I shall highlight some challenges for clinical moral discourse, given the recent developments in direction of competitiveness and reimbursement models.

Professionals deal with moral issues. Professionals perform good/useful actions in a competent manner. The technical excellence is freely discussed among professionals, but moral issues are more difficult to raise. Disagreement and mistakes have traditionally been kept within the profession. Difficult moral decisions must be handled privately. Thus, professionals are no strangers to the phenomenon of moral muteness, i.e. not encouraging (or even discouraging) discussion of topics of moral import.

The introduction of new public management models in health care challenges the autonomy of the medical profession as well as individual professional judgment. In Norway, models for the rationing of health care have been difficult to implement, in part because of professionalism. Criteria of efficiency and reimbursement schemes seem to fare better from a bureaucratic point of view. One would believe that such a threat to professional judgment would be countered by a fierce debate about values. In Norway,

this has not happened. One possible explanation could be that for instance the DRG system is perceived as fair and in line with professional values. There are, however, many examples showing that this is not the case, and that DRGs sometimes provide incentives to provide less than optimal care.

In his discussion of the phenomenon Frederick Bird claims that "moral talk" pose a threat to the equilibrium at the workplace: focus on values and morality enhances the awareness of what suboptimal solutions. Furthermore, such talk is a threat to efficiency, because such discussions require time which must be subtracted from the primary activities. Increased awareness and distractions give managers less flexibility. It becomes harder to take moral shortcuts, even if seen as necessary from a pragmatic perspective. To encourage moral discourse is therefore not productive, and productivity *is* important. The consequence of moral muteness is that it becomes difficult to address moral issues on a broader scale. Morality becomes a private issue. Value-laden problems lead to moral stress for professionals who must make moral choices that are not recognized as such. How new public management models increase this predicament is the main aim to demonstrate.

DEFINITION OF HEALTH: THE ALTERNATIVE NOTION

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Definition of health: the alternative notion

The entrenched definition of health as it was issued by the WHO has been often criticized or even mocked because of various reasons. Actually the most precarious point in it is its core rendered by the term 'well-being' which is considered either too empty or too hedonic. Hedonic it becomes and indeed loses its content particularly if we fathom it as contentedness or even happiness wherefore its meaning starts to be rather volatile with paradoxical consequences. Contemporary medicine thus requires another account of what health is. Since health is something that by its nature ought to be, we should be aware that sciences are in this regard of almost no weal.

In fact we need a definition that would not be codified but procedural as we find it in philosophical ethics and the presentation will offer one possible solution regarding the crucial trait that permeates biological, psychological as well as ethical level. Actually this trait that manifests itself for example in the capacity to take a risk is not cherished by the modern medicine that far. We are thus to be aware that also medicine at large would be urged to mold itself in a different way if this definition were acknowledged. However this definition concerns particularly the notion of the human being that should be treated as being turned by its will to the future in which the proper human motives dwell. The presentation will sketch some basic principles of this approach (supported by the Grant MSM 0021620806).

ALLOCATION OF PUBLIC SOURCES IN ONCOLOGY: ETHICAL ISSUES AND THE ROLE OF HOSPITAL ETHICS COMMITTEE?

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The share of health care expenditure allocated to cancer is now significantly lower than the share of the burden of the disease. Health care costs for cancer are dominated by costs for inpatient care but a matter of concern is that the introduction of new innovative cancer drugs will result in an increase in costs, both in absolute terms and as share of total health care costs. This out of hand boost and a lot of the social and economic factors (such as getting older, having fewer children and working without a fixed income) impose an 'expenditure rethinking' which, however, cannot be only a saving costs instrument but should take into account results and consequences of future allocation choices and should respect a complex value system. In particular, more than other branch of Medicine, Oncology involves life and death decisions and many possible treatments have an amount of uncertainty. In this perspective, important questions emerge: how to face change? How should economic evaluation be integrated with ethical evaluation? Is this achievable? In our work we will discuss the ethical dimension of health care rationing at several levels and illustrate other ethical instruments to face allocation of public sources in Oncology. At micro level (the so called 'bedside rationing') an important instrument can be the ethics consultation. At meso level, the Hospital Ethics Committee can help the Hospital Healthcare management Department, using its competences to indicate working indications in the course of rationing and allocation process. Besides, attention should be devoted to integrate micro level with meso level in order to guarantee a proactive ethically justifiable rationing. The Hospital Ethics Committee through ethical guidelines on critical aspects, for example end of life decisions, and coordinating multidisciplinary groups could support a collaborative process to define priorities and an ethically allocation of resources.

BLOCKBUSTER DRUGS' PATENT RETIRIES. WHAT DOES THE ECONOMIZING EFFECT INFLUENCE? A DECISION-MAKING ANALYSIS.

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Background: Several big-selling drugs (Lipitor/Sortis; Zyprexa, Plavix, Seroquel) will loose patent protection in some months. In view of the fact that e.g. Lipitor had 2007 sales over \$11 billion, the economizing potential of these patent retiries is substantial. This work analysis the decision-making, which is vital to switch to generic drugs.

Methods: Analysis of the decision-making on the level of the patient and the doctor. Influences by the health care system conditions (e.g. in Switzerland) and the current research on decision-making are involved.

Results: The principle of „loss aversion“ is determining whether a switch towards generic drugs take place or not. The central point of this principle (D. Kahneman, Nobelprize 2002) is that losses have greater impact on preferences than corresponding gains. This endowment effect increases with time (Knetsch,1990). Poldrack described the neural basis of loss aversion in decision-making under risk (Science, 2007). People value expensive drugs as more effective than cheaper ones (Dan Ariely, JAMA 2008). In Switzerland the use of generic drugs took a leap, when the patients themselves had to pay the double amount for the original drug than for the generic one (2006). Halving of the price of Risperidon versus competitors did the generic drug company Teva not bring more sales in Switzerland (2010).

Conclusion: A low price is not by itself a sales argument in the field of medicaments. Because losses loom larger than corresponding gains the decision makers (patients; doctors) do only switch to the generic drugs, if the individual loss/gain-balance falls towards these medicaments. Thereby there are several obstacles, such as the endowment effect. Patients who are pleased with their medicaments und trust them would not like to change to others. The main effect of endowment is not to enhance the appeal of the one owns, only the pain of giving it up. That hospitals often endow patients with original drugs do not help to promote the cheaper generics. The hospitals do so, because they normally can receive the original drugs for vantaged conditions. The manufacturers of original medicaments hope probably for the endowment effect on the patients by offering nice prices to the hospitals. That people trust more the expensive drugs than the cheaper ones is unfavourable for the generic drugs. These obstacles seem only to be bridgeable if the decision makers themselves would face to noticeable financial disadvantages in case they would prefer the original drug to the generic one.

THE PRIORITY IN DISASTER MEDICINE: THE CRITICAL QUESTION OF PALLIATIVE CARE

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When a disaster happens, where the intervention of health care system is needed, the discussion is mainly focused on allocation of scarce resources, with much less attention given to basics of palliative and dignified care to victims we cannot save anymore. Usually they are the weakest people as elderly, chronically and terminally ill persons. This kind of situation is due to a worldwide inadequate policy of palliative care in which healthcare efforts are directed at curative and high-end care, often at the expense of basic, humane care, as embodied in palliative medicine.

We argue that the shift of the paradigm of medicine from beneficence to autonomy is affecting the capability of the professionals of health to take care of the diseased where there is no more possibility to cure. Instead we are convinced that beneficence should have the prominence in the clinical setting and should be a very useful guide when a plan is required to answer to the needs of population in the face of a disaster.

HEALTH CARE DIMENSION OF HUMAN RIGHTS IN GEORGIA

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After the collapse of the Soviet Union, Georgia was restored to political independence. In the transitional period, the government of Georgia has carried out several reform initiatives for building a more effective health care system.

The Soviet model left as its heritage a health care system with no legal basis, grounded on a paternalistic model of doctor-patient relationship, and a tradition of isolating people from health care, leading to society in general being indifferent about it.

In 1995, a new conception of health care reorganization was elaborated in Georgia, in which the political, economic and judicial components of state policy of health care were defined. The most important of them was to create a legal basis that would change the health care system, from one exclusively focused on medical institutions to a system focused on patients.

Since 1995, the Georgian parliament has passed many important laws, including laws in the medical sphere and laws to regulate social problems. The overview of current legislation and health indicators reflects the new health care dimension of human rights in Georgia: access to health care, protection of health, rights and dignity of patients.

THE IMPACT OF MANAGED CARE AND CLINICAL RESEARCH ON CLINICIANS

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Hypothesis: The practice of medicine in U.S. academic centers is changing dramatically under the influence of managed care and clinical research. Observations: 1-A successful physician is the one who takes into account the pressure coming from numerous controlling institutional policies and financial constraints for profit healthcare insurance companies. Hospital managers should focus on the healthcare delivery processes, but have the temptation to influence directly the clinical goals and the professional

practice. The healthy gap between clinical goals and outcomes for very diverse patients will not survive to a chain production model. 2- If research is the general collection and aggregation of data that permits conclusions to be drawn, and develops or contributes to generalizable knowledge, the practice of clinical research brings a methodological interest in the way medicine is practiced and evaluated. But real medicine deals with individuals for whom something has to be done according to the best available medical standards. The requirements of science without a sound clinical judgment can lead to a pure methodological approach (a central line was successfully put in place in accord with the protocol but patient died of his illness), or favor a population approach to the detriment of individuals. Conceptual Model: Because there is no simple solution to a complex problem, the “incompletely theorized agreements” approach of C. R. Sunstein (*Legal reasoning and political conflict*, 1996) and J. P. Ruge (*Aristotelian justice and health policy: capability and incompletely theorized agreements*, 1998) can be helpful in building a consensus oriented towards action, a practically oriented discussion, that allows agreement at the conceptual, policy and intervention levels.

WHAT DEFINES MINIMAL RISK IN BIOMEDICAL RESEARCH? A CRITICAL REVIEW OF EXISTING CONCEPTIONS OF MINIMAL RISK

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The ethical acceptability of clinical research critically depends on protecting participants from excessive risk. Most commentators, and essentially all research guidelines and regulations, agree that it is acceptable to expose research participants to some risks for the benefit of others, provided 1) the risks to participants are “reasonable” in relation to the potential benefits for them and/or the potential benefits of the generalizable knowledge gained in the study, and 2) the risks to participants are no more than “minimal” when the study offers no prospect of direct benefit and fully informed and voluntary consent is not or cannot be obtained. Unfortunately, there is no recognized definition of minimal risk in clinical research. This situation has led to considerable variation in which risks are considered minimal, raising concern both that research participants may sometimes not be protected from excessive research risk, and that other times valuable studies involving acceptable risk may be rejected.

To improve this situation, this presentation aims to clarify the concept of minimal risk in biomedical research. The presentation will systematically review and critically analyze the existing conceptions of minimal risk articulated both in the scholarly literature and in research regulations and guidelines. It will be argued that it is helpful to classify the existing approaches to defining minimal risk in three groups: 1) *compiling intervention lists* (e.g., the non-invasive collection of excretions or secretions, the collection of

blood from existing peripheral catheters, etc. are declared to be minimal risk interventions), 2) *specifying the meaning of minimal risk* (e.g. minimal risk interventions pose “no risk of serious harm”), and 3) *invoking risk comparisons* (e.g. minimal risks in research are no greater than the risks of daily life). Although none of the existing definitions of minimal risk are convincing from a conceptual and/or normative point of view, important lessons can be learned from their shortcomings. In particular, risk comparisons, if properly refined and constrained, seem to have the greatest potential for developing a sound and workable definition of minimal risk in biomedical research.

BIOETHICS VS. THE MARKET: MYRIAD GENETICS, BRAC1-2 AND MORALITIES IN CONFLICT

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The March 2010 court ruling in which Myriad Genetics’ (Myriad) patent on the BRAC1 and BRAC2 genes and the concomitant testing and analysis (BRACAnalysis) protocols were invalidated offers insight into the conflict between one moral (fiduciary) system based primarily upon stock valuations, dividends and the ability to attract venture capital, and another based primarily upon the imperatives of the physician-patient relationship.

Myriad was challenged on the legitimacy of a number of claims arising from their patents on the BRAC genes, which fell into two broad categories: (1) their claim to exclusive rights to test for genetic mutations associated with breast cancer (BRAC1) and ovarian cancer (BRAC2), which rights derive from (2) their ownership of the genes themselves, owing to their claim of having (a) identified them and (b) isolated them. The legal challenge brought by a class of plaintiffs including the American Civil Liberties Union (ACLU), researchers, physicians and patients argued against these claims, and against the principle of private ownership of human genes.

Myriad argued that a ruling against them would have a chilling effect on genomics research, especially in that investors would be reluctant to fund research without the expectation of a reasonable return on their investments, mainly in the form of exclusive intellectual property rights over a “predictive medicine product” that all women with the salient risk factors (and the appropriate financial resources) would be encouraged to use. The suit against their patents was an affront to their business model and the overall ability of the biotechnology industry to attract venture capital. The imperatives of treating illness were neither at nor near the top of their list of priorities, as Myriad stated them.

ACLU in challenging Myriad’s patents argued in favor of access to the BRAC Analysis protocols, so that more women would have access to what is acknowledged to be a significant breakthrough in early diagnosis — and therefore a greater probability of successful treatment — of breast and ovarian cancer;

and, further, that broader access by researchers and clinicians would lead to improvements in the protocols, including the availability of second opinions. ACLU, therefore, argued on behalf of women's health, and on behalf of the researchers, clinicians and genetic counselors whose ability to advance both the science and the healthcare was compromised by their exclusion from the current state of the art.

Even though biomedical research, pharmaceutical research and development, and the practice of medicine itself ("predictive" or otherwise) are extraordinarily expensive, is it possible that there exists a fundamental ethical incompatibility between certain types of intellectual property rights (Myriad's position as stated in court documents is that DNA is just another chemical compound) and healthcare delivery? Myriad's patent claims are also under challenge elsewhere (Europe, Australia), and even though it is hardly possible that the principle of gene patenting can be overturned, the present interregnum in litigation (Myriad vs. ACLU is under appeal in the US) might be considered an opportunity to evaluate the dichotomy on the ground of healthcare ethics rather than business ethics.

ENHANCEMENT, PERFECTION AND THE GOALS OF MEDICINE

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The distinction between therapy and enhancement is often regarded as crucial to the moral evaluation of enhancement: While the therapeutic use of medical technological means (in order to preserve and restore health etc.) is said to be unproblematic, their use for purposes beyond therapy is judged to be prima facie problematic and in need of justification. Many philosophers, however, have raised doubts about the distinction between therapy and enhancement and its prominence in the debate – arguing that it is not a clear-cut, but rather a blurry and gradual distinction that is essentially contested, and questioning its moral importance. Some philosophers have even contended that we should altogether abandon the distinction between therapy and enhancement.

In our talk, we examine the reasons for and against abandoning the distinction between therapy and enhancement in the debate about human enhancement. On the one hand, we suggest that an outright rejection of this distinction might undermine a sensible discussion about the "goals of medicine", which has been opened up again by the possibility of new medical technological interventions. After all, restoring health or normalcy, as difficult to define it may be, is quite different from improving capacities to a degree humans never had before. On the other hand, however, we argue that giving the distinction between therapy and enhancement too much importance might inhibit fruitful discussions about enhancement, because enhancements are potentially not only a challenge for medical practice: If we define and evaluate enhancement only by contrasting it with therapy, we lack a positive idea about the

goals of enhancement in its own right. Here we suggest taking a closer look at the concept of "perfection". We investigate whether this concept proves helpful to reframe discussions about enhancement, when it is conceived more broadly as a social and individual challenge: Does it enable us to engage into a (necessary) discussion about the 'proper goals of enhancement', or is it nothing more than a notoriously vague notion and a "red-herring" in the debate, as some philosophers have claimed?

HUMAN ENHANCEMENT AND DISABILITIES

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Since the outset of the XXIst century, the topic of human enhancement has firmly entered into the political and scientific agenda. In a very near future, enhancing technologies could play an important role in a variety of different domains: from genetics to sport, including the enhancement of cognitive and emotional capacities, modification in the length and style of life, or opening new opportunities in the domains of intracorporeal prostheses and brain engineering. Human enhancement implies in particular a change of paradigm in the medical practice. But the main question it poses is not related to this change that already occurred some time ago. If the distinction between curing and enhancing is discussed, and, because the same technologies are used in both cases, often contested, there is no doubt that the aims of classical therapeutic medicine, of enhancing medicine and transhumanism, as diverse as they are, lend us to question human life in its relation to norms. According to the aims that are pursued, the norm (in a biological, social or existential sense) can be restored, optimized or enhanced. Yet, when these three goals will be simultaneously or completely aimed at, people whose life differ from the norm risk to find themselves very far from what we will consider in the future to be a « normal human life ». They will be separated from normal human life at three degrees: one degree separate them from the basic human functioning, the second from an optimal human functioning and the third from the enhanced human functioning.

We want to concentrate here on the implications of enhancing technologies for disabled people. Considering the risks of exclusion, the development of a « morality of inclusion » represents a fundamental ethical requirement. The scientific literature on this topic tends however to concentrate on the problems associated with predictive medicine (prenatal and preimplantation diagnosis in particular). Enhancing technologies are thus conceived as permitting to prevent individual impairments (mental, physical, intellectual, etc.); and the oppositions coming from the disability rights movement, that bases his discourse on the argument called « the expressivist objection », are made on behalf of the non-discrimination principle with the fear of eugenics in the background. Contrary to this trend, we would like

to concentrate on the existing individuals who are now suffering; on the persons with multiple disabilities (multi - or poly-handicap) who, for reasons we will analyse, risk being the rejects of the promises offered by the new technologies.

'INTENTIONAL DIMINISHMENT' AND THE INTERNAL MORALITY OF MEDICINE

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In 2002, the "Washington Post" published an article of a couple of lesbians – Sharon Duchesneau and Candy McCullough, both deaf from birth, who deliberately underwent artificial insemination using sperm from a donor with five generations of deafness in his family, in order to conceive a deaf child. The story evoked many controversies and critical comments. However, as many media reports and empirical research show, cases of intentionally creating disabled children through selection of gametes or embryos are not rare nor unusual. Wertz et al. (2002) found that 7% of geneticists in the US, 21% in Australia, 25% in Norway and 20% in Portugal faced requests for prenatal diagnosis from parents who wanted a child with the same genetic condition as themselves, usually [AJOB 2002, 2(4)]. According to a study performed by the Genetics and Public Policy Center at Johns Hopkins, 3% of American infertility clinics surveyed reported that they had intentionally used PGD to identify and implant embryos with a particular disability [Baruch et al., Fertility and Sterility 2008, 89(5)].

The purpose of this presentation is to examine whether medical professions should engage into 'intentional diminishment' practices; whether they should use gamete selection or PGD to choose for a (significant) disability? The issue will be discussed in the light of the internal morality of medicine defined as a moral framework consisting of goals proper to medicine, role-specific duties, and clinical virtues [Miller, Brody, Journal of Medicine and Philosophy 1998 23 (4) & 2001, 26(6)].

I will argue that since these practices have nothing to do with treating or preventing a disease or pain (e.g. resulting from infertility), they do not serve the goals of medicine. Contrary, they may be accused of causing harm to the future offspring, although not in a standard, counterfactual sense of the notion, but in an alternative one (i.e. transpersonal harm, absolute harm, harm based on rational preferability, *prima facie* harm, or threshold harm). Their performance by physicians misrepresents medical practice by suggesting that it is proper for a physician to create and promote disability. In sum, I will argue that 'intentional diminishment' falls outside the moral framework which constitutes internal morality of medicine, and as such should not be performed by medical professionals.

PARTICULARISM AND PRIORITY SETTING: DOES THE FAIRNESS OF OUR PRIORITY SETTING DECISIONS DEPEND UPON US REASONING FROM A SUITABLE SUPPLY OF ETHICAL PRINCIPLES?

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One school of thought in the current literature on priority setting argues that the ‘fairness’ of our priority setting decisions depends upon us reasoning from a suitable supply of substantive ethical principles. These may include utilitarian principles such as ‘maximize health’, or more egalitarian principles such as ‘distribute in proportion to degree of immediate threat to life’ (cf. Cookson and Dolan, 2000). The job of priority setters, therefore, is to articulate which principles are to be considered, decide which principles are ethically appropriate for consideration, and balance the claims of competing principles against one another.

This has been challenged in recent years by writers such as Daniels and Sabin (1998). They argue that in order for our decisions to be fair, we do not need to reason from a set of ethical principles. Rather, the fairness of our decisions can also be guaranteed through the use of a fair process. Daniels and Sabin do not question the idea that fairness *can be* guaranteed through the use of ethical principles, rather they simply argue that in absence of such principles, it can *also* be guaranteed through a fair process.

Particularism offers us another way of thinking about fairness in priority setting. According to this position, one can reach a fair decision even if one does not reason from a suitable set of ethical principles, and even if one does not use a fair process. This is because, as Dancy puts it, ‘there is no reason whatever to suppose morality stands or falls with a supply of principles capable of doing the job required of them’ (Dancy, 2004). Rather, we can get along perfectly well in priority setting without such principles, even in absence of a fair process.

Building on Dancy’s work, in this paper I set out what a particularist priority setting process might look like and consider some of the challenges it might face, most notably Rawls’ worry about inconsistency. I argue that any particularist priority setting process would face an uphill struggle in the face of public opinion. However, I also claim that particularism does accord with one powerful intuition we may have about prioritizing health care resources, namely the idea that reason for action which is relevant in one case is not *necessarily* relevant elsewhere. In this respect of this intuition, I argue that far from helping us to resolve priority setting decisions, the use of substantive ethical principles actually lead to a distortion of the decision making process.

OF PREVENTION AND ENHANCEMENT – TWO SPINS BEARING ON THE GOALS OF MEDICINE

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It is claimed that prevention strategies in medicine should be paid more attention to than had been the case before. The case for prevention is mostly based on economic calculation. The idea behind is that a considerable amount of money spent by society could be saved if people will not have to be treated for conditions that may be prevented by medical surveillance of seemingly healthy persons. The other field of extending medical practice is the idea of enhancement technology. There are two major areas where enhancement is discussed: neuroenhancement and genetic intervention, e.g. using preimplantation genetic diagnosis and respective intervention.

Prima facie both the fields of medical endeavors seem not belonging together. Yet, in that paper I will discuss how the arguments brought forward in favor of both may undermine the basic motivations and principles that have been essential to medical practice so far. E.g. with respect to prevention economic justification may i: turn out to be erroneous, ii: disintegrating basic as well as intermediate ethical principles. And as well efforts to enhance human condition contradict ethical principles in medicine in various ways. E.g. even utilitarian arguments have not provided convincing accounts which attributes and capacities will enhance outcome effects as the idea of what is aimed at is beyond any utilitarian calculus. In addition, reference to autonomous decision making in this field will not neutralize this objection as it may i: promote concepts of eugenics involuntarily and ii: destroy basic motives such as the intuition to heal as had been worked out by E. Levinas and others. Efforts to justify prevention or enhancement by referring to choices made by individuals only is limited by the idea of medical practice as promoting a common good (Plato).

In conclusion, some of the activities under the flag of prevention and enhancement may be sanctioned as they contradict other basic values, such as justice, freedom and right to live. While others may not be sanctioned yet should be excluded from medical practice. Finally, before including some strategies into medical practice their ethical impact has to be examined carefully.

INDIVIDUAL RESPONSIBILITY AS A GROUND FOR PRIORITY SETTING

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In the recent discussion on priority setting in health care the aspect of individual responsibility have received increased attention, especially pertinent in the discussion on luck-egalitarianism, where it is

argued that the patient could be down-prioritized if having suffered ill health as a result of having made choices that could have been avoided (having suffered so called option luck). This idea has received well deserved critique for a number of reasons, where the most important are the problem of establishing a causal connection between earlier choices and individual ill health, the problem of whether the patient actually can be blamed for these choices and the problems this could imply for trust etc. in the clinical encounter. Another current trend in how to organize the health care setting is the push for shared decision-making (SDM) involving the patient in clinical decisions to a greater degree – both for reasons of strengthening patient autonomy and for reasons of achieving better adherence to treatment and care. It has been argued that pushing for SDM imply that we should accept invoking individual patient responsibility as a factor to take into account in priority setting, since if the patient is trusted to be able to make decisions and act responsibly upon these, shouldn't the patient also be made responsible for choices made after this clinical encounter that will result in ill health. In the talk the relationship between SDM and the values underlying SDM and individual responsibility in priority setting is explored. It is argued that accepting more dynamic versions of SDM imply accepting the patient to be *able* to take responsibility for his health and health-care. It is further argued that a prospective view on individual responsibility after SDM will avoid some of the critique made against the use of individual responsibility as grounds for prioritizing between patients, but also reveal a possible internal tension. The prospective use of individual responsibility after SDM will be explored in relation to different theories of distributive justice, thereby giving grounds for assessing how to handle the possible tension and balance between the clinical ideal of SDM and justice.

CLINICAL PRACTICE GUIDELINES HAVE NOT YET TAKEN US UP TO PROFESSIONALISM'. WHY AND HOW CLINICAL PRACTICE GUIDELINES SHOULD ADDRESS DISEASE SPECIFIC ETHICAL ISSUES

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Background: Clinical practice guidelines (CPG) aim to improve standards of clinical competence. To date, however, CPG development manuals fail in addressing methods for the systematic and transparent integration of disease specific ethical issues (DSEI). DSEI, their acknowledgment and explicit handling are deeply intertwined with the concepts of clinical competence and professionalism.

Objectives: 1) To demonstrate why CPGs should address disease specific ethical issues; 2) To develop a theoretically saturated framework of DSEI for dementia and chronic kidney disease as core requirement for the systematic integration of such DSEI into CPGs.

Methods: A systematic review of ethics literature on dementia and chronic kidney disease was performed. The included literature was then analyzed qualitatively in order to develop a theoretically saturated framework of DSEI.

Results: The rationale for having CPGs addressing DSEI has been outlined in the Background. The talk will further elaborate this rationale. Fifty-seven references for dementia and 32 references for chronic kidney disease were included in the qualitative analysis, which produced 26 and 18 DSEI for dementia and chronic kidney disease, respectively. For both diseases all DSEI could be grouped under 7 main categories (indication, patient information, patient decision making competence, proxy decisions, social and context related aspects, clinical conduct, and evaluation). We present the DSEI frameworks and discuss further methodological approaches for using these frameworks in CPG development.

Discussion: Systematic reviews of DSEI together with thematic analysis provide the scope of DSEI. Such DSEI frameworks should build the basis for a systematic and transparent integration of DSEI in CPGs (see abstract of Knüppel H et al.). Further research needs to clarify how guideline development groups should select the most relevant DSEI and then draft ethical recommendations in a systematic and transparent manner.

TO BE OR NOT TO BE...HONEST: ISN'T *THAT* THE QUESTION?

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The discourse of health care rationing is littered with euphemisms, subterfuge, and mysterious equations and formulas. Although we say we allocate health care resources, what we're really allocating is death and suffering. Although we say it has to do with distributive justice, what it really has to do with is distributive injustice. Truth be told, the entire enterprise rests on the belief that we can discriminate among everyone who needs health care without discriminating against anyone who needs health care, as if it were the case that we were omniscient. Assuming for the moment that it might be a good idea to replace hubris with humility, the question that confronts us is not whether we can afford to make these decisions honestly, but whether we can much longer afford *not* to do so.

PRIORITY AND COST-EFFECTIVENESS BY NICE IN THE UK: SAME OLD NICE STORY... RESEARCH, RESOURCE ALLOCATION AND COST, WHAT COST?

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The National Institute for Clinical Excellence (NICE) recommends and gives guidance to the UK National Health Service on a range of health implementation issues, but more often than not, appears in the public eye regarding issues of funding and resource allocation for the National Health Service (NHS), usually in a negative light. For example most recently regarding the removal of funding support for the distribution of the bowel cancer drug Avastin. With bowel cancer being the third most common cancer in the UK, this generates some strong and polarised debate. The debate in this case however seems to be stuck in a framework of utility vs deontology rut- With the UK bowel charity claiming that all treatment options should be ruled in regardless of cost, and NICE Chief Executive Sir Andrew Dillon claiming that benefits offered in the treatment justify the costs that the NHS has to pay. Is there a way out of these competing demands- the health demands of the individual, as opposed to the availability and distribution of a resource? Seemingly contrary to the refusal to support Avastin distribution on the NHS, NICE has published on its website, a journal article that claims that its guidelines are the most “trustworthy in the world.” (http://www.nice.org.uk/aboutnice/howweare/who_we_are.jsp). So how does the idea of trustworthiness square with the case that for some bowel cancer sufferers, NICE even see things *only* in cost/distribution/need terms? Perhaps there is something about NICE’s setup and remit that is more likely to disappoint as the media stories suggest. However NICE states that it was set up to “...ensure everyone has equal access to medical treatments and high quality care from the NHS- regardless of where they live in England and Wales.” (NICE, referring to editorial published on 10th June 2011 in *Annals of Internal Medicine* on the prevention of delirium).

REGENERATION AND BIOMYTHOLOGY

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Regeneration is a recurring theme in several areas of new biotechnological advance, most evident in stem cell research and frequently can be read in association with the use science fiction terminology in press releases, often found with the tag line: ‘what was science fiction is now becoming reality’. The UK tabloid The Daily Mail ran an article in Feb 2011 on a ‘star trek skin gun’ used in new skin graft technology; a recent series of adverts for cancer research on UK television saw a woman having a conversation with a zebra fish, concerning its ability to regenerate cardiac tissue. The fish in its ability is identified as not just a fish, but as ‘hope’. The advertising campaign started the very day that heart

research into zebra fish was announced again on BBC news, initially as an independent news item, but then linked directly to the research campaign under the heading ‘Mending Broken Hearts’. In this presentation I will look at the extent to which biomythologies are generated in relationship to accurate scientific accounts, with the aim in this case of soliciting research funding donations from the general public. Is there a line to be drawn regarding the manufacture of myths to achieve research aims, pulling at the potential donor’s heart strings?

SURVEILLANCE VERSUS RESEARCH ETHICS: TECHNICAL DISTINCTION OR MORALLY RELEVANT DIFFERENCE?

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Often referred to as “the eyes of public health”, surveillance is widely considered to be one of the most basic public health activities. The role of surveillance in global health policy has recently been magnified by the new WHO International Health Regulations’ call for increased infectious disease surveillance. The drive for increased surveillance is largely motivated by the growing problem of emerging and re-emerging infectious diseases in recent decades and fears regarding bioterrorism. Recent technological advances, meanwhile, have facilitated improvements in surveillance capabilities. Though health surveillance is closely related to medical research—and though they often involve the very same activities (e.g., medical record review)—the two are treated much differently in practice. While the requirement of voluntary informed consent is a central tenet of research ethics, for example, many would argue that informed consent is neither ethically required for—nor compatible with the goals of—public health surveillance. Bioethics to a large extent grew out of research ethics, and research ethics is one of the best developed areas of bioethics. The situation regarding surveillance ethics at present, however, is similar to that of research ethics prior to 1947 (when the Nuremberg Code was established). While guidelines for the ethical conduct of public health surveillance and/or relevant oversight mechanisms are therefore needed, their development requires (1) clarification of the technical distinction between research and surveillance and (2) analysis of whether or not, or the degree to which, there are morally relevant differences between the two. This paper argues that if any two activities are equal in the extent to which they are expected to yield (public) health benefits and (estimated to be) equally risky to the subjects of the investigative activity in question, then the two activities should be subject to the same requirements regarding human subject protection (regardless of whether one of the activities is technically considered to be research, and the other surveillance).

IS IT ETHICAL TO INCENTIVISE STERILISATION?

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Project Prevention is an organisation founded in 1997 with the express purpose of “*offering cash incentives to women and men addicted to drugs and/or alcohol to use long term or permanent birth control.*” (1) To date it has paid money out to 3,388 ‘clients’ who have agreed to a range of contraception’s. This discussion will focus on the 1307 individuals who have had permanent sterilisation, it aims to focus on the *act* of incentivising people to have the intervention as oppose to consequences of the intervention itself. The framework for Project Prevention is to give selected women the option of having some form of contraception (long-term or permanent) with an incentive of \$300 to undergo the procedure. The women are selected based on how many pregnancies they have had before, how many miscarriages they have had and how long they are considered to be drug addicts. One of the core issues in our discussion is whether the individuals being sterilised have had the *opportunity* for a fair and honest decision? How, if at all, has the monetary incentives affected this process and to what end can this effect be considered ethical? Personal financial incentives are increasingly being used to motivate patients and general populations to change their behaviour, most often as part of schemes aimed at reducing rates of obesity, smoking, and other addictive behaviours. (7) For drug addicts can autonomy exist and be utilised on a decision based on the procurement of drugs? Is it ethical to incentivise sterilisation? The decision making process that participants of incentivised sterilisation have to make is fraught with conflict and dilemmas. How at a glance it appears Project Prevention is simply making an alternative available, in reality the influence exercised by the offer is manipulative, coercive and exploitative, exerted on vulnerable, easily motivated individuals with relatively little to gain other than an opportunity to satiate their drug addiction. The activities of the organisation Project Prevention whilst altruistic in intent leaves many questions unanswered. It crosses a very tangible threshold and could very well be the distinct line that moves us towards a less tolerant society.

WHAT ARE THE SOCIETAL CORRELATES OF GOOD VERSUS BAD HEALTH AMONG THE NATIONS OF EUROPE?

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Background: An Oxford economist recently introduced to the study of his discipline the term "Bottom Billion" ascertaining how the poorest nations of the world differ from wealthier nations. Can this same methodology be used to distinguish nations or states based on health status?

Methodology: A scale was established that assessed the health of the nations of Europe using life expectancy, infant mortality, and mean daily years of life (DALY) morbidity. The scales used largely WHO published indices, were standardized and scaled with high results representing better health status and the top and bottom quintiles were demarcated. Indices used to assess cofactors influencing health were also largely WHO-derived and included smoking rates, alcohol rates (based on total yearly mean consumption), mean per capita income, population size, percentage who drive regularly (at least once a week), and the presence of a major conflict after WWII. A similar set of indices were carried out for the American states.

Results: The most complete and recent data for these indices were from about 2004 with data available from 47 of 51 European jurisdictions. The results for the composite health index ranged between 16 and 64, with the 3 lowest values from Azerbaijan (16), Turkey (27), and Romania (29) (also Kazakhstan (23) controversially European) and the 3 highest from Sweden (64), Iceland (63), and Malta (61). The nations among the bottom quintile in the health care index tended to have residents who smoke tobacco more (mean rates were 32.7% vs 29.2%, NS), drink alcohol less (mean 5 L/y vs 10 L/y, $P < 0.005$, Kruskal Wallis), were involved in a major conflict (67% vs 29%, $P = 0.04$, Fishers), show a substantially lower per capita income (USD 10,929 vs 27,217, $P = 0.001$, KW), and drive less often (weekly driving by 29.5% vs 60% of the adult population). In a multivariate regression analysis using data from 34 nations, three variables that significantly correlated with health care indices were per capita income ($P = 0.001$, correlation coefficient = 0.75, with healthier nations being significantly wealthier), prevalence of obesity ($P = 0.007$), and the prevalence of smoking ($P = 0.037$). In an analysis of the American states with similar regression techniques, states in the lowest quintile of health indices showed significantly higher rates of smoking ($P = 0.042$) (Smoking rates for Europe are higher, 30% mean overall vs 20% for America). American states with worse health indices also tended to be former slave-holding states of the South ($P = 0.001$, KW).

Conclusion: Among the nations of Europe, per capita income, obesity rates, and, to a lesser degree, smoking rates are major determinants of an overall health parameter comprised of life expectancy, infant mortality, and overall morbidity using mean annual days of life lost. Smoking was more strongly correlated with poor health indices in the American analysis. An implication of these findings is that while improved wealth correlates with better health, the appropriate use of wealth (in avoiding smoking or excess weight gain) is needed to maintain health.

HERMENEUTICS AS A TOOL FOR APPLICATION OF THE HUMAN RIGHT TO WITHDRAW FROM HEALTH CARE

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At the first glance the human right not to be object of involuntary applied health care is well guaranteed by the institute of informed consent. However there are situations in health care, where traditional understanding of physician's role gives no chance the patient to control his/hers treatment. In emergency situations and in all other conditions where a patient is in a state of severe distress or in a state of disturbed consciousness physicians apply treatment according to "lege artis" procedures without regard to patient's wishes. All attempts to solve this problem are problematic. The patient is considered as a person non competent to put through his wishes and there is nobody else recognized as competent to stop the treatment. Advance directives do not fully solve the problem, because they are not always directly applicable in concrete situation. Future patient cannot foresee all circumstances which would occur. A good solution could be appropriate use of hermeneutics. Advance directives elaborated in a narrative way could be considered as a text which needs hermeneutic interpretation. Interpretation of patient's text is not easy. Information on attitudes and values of the patient are incorporated in the text. At least three perspectives should meet in its interpretation: physician's perspective of biological medicine, nurse's caring perspective, worries and expectations of family members. A small conference of all concerned is better solution than decision made by a single person be it physician or patient in his advance directive.

JUSTICE AND PRIORITIES IN THE ISRAELIAN HEALTH CARE SYSTEM

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According to a report for the European Observatory on Health Systems and Policies the Israeli Health Systems is in 'transition' (Rosen and Merkur, 2009). While the Israeli health care system is looked upon by some people as one of the most advanced health care systems in the world in terms of access, quality, costs and coverage (Zimmerman 2009), at the time of writing this abstract (June 2011) the Israeli Medical Association (IMA) is leading a strike in order 'to save' the Israeli public health. This paper will describe the Israeli Health Care System, the criteria for setting priorities for the expenditures on health care, the values underlying these criteria, and will analyze new developments and the allegations of IMA.

SHOULD 'ONE HUNDRED PERCENT UTILIZATION' OF IVF BE THE 'NORTHERN STAR' FOR IVF POLICY?

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This paper reviews the literature dealing with IVF outcomes, policies and practices; analyses the effectiveness of IVF cycles over time; examines women's health and welfare after long-term IVF use; and asks whether in a scheme of unlimited free-access to IVF (one hundred percent utilization of IVF), women would necessarily be better off. Results: long-term effectiveness with IVF is unclear. Age and number of unsuccessful IVF cycles are predictive of a negative outcome, which is at odds with the Israeli policy of open-ended rounds. Conclusion: a systematic long term assessment of the health and welfare of the women after IVF - especially after prolonged treatment with IVF – is necessary to develop a reliable, effective and evidence-based policy on assisted reproduction; not only in Israel, but also in other countries.

HUMANKIND SURVIVAL: BIOMEDICINE AND POLITICAL BIOETHICS

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Scientific and technological developments in the fields of genetics and biomedicine lead to radical changes in the evolution of humanity. Among these changes there is a risk of biointellectual domination of the entire humankind by a social elite detached from existing social institutions and components, by self enriching, self supplying and self assuring, with new abilities much superior to common individuals, especially through nanogenetic technologic cultivation and selection. This special social category, little by little, as discreetly as possible, begins to gather all characteristics of new biological brunch. Such perturbations threaten for human individual independence and integrity and for family and group life, as well as global peace and justice. Public opinion is at the beginning of the process of understanding possible negative results of a blind implementation of human genetic engineering.

In this context, it is necessary to found a new branch of bioethical science – *political bioethics* as an additional innovative bioethical dimension in the applied methodological arsenal of establishing and implementing the theory and practice of humanhood survival. Political bioethics appears as one of bioethical branches, concerned with the study of different political aspects, implications and consequences of new biotechnological developments. The biomoralization of political life concerns subordination to higher global imperatives of political will, social strategies and policies. It concerns as well the implementation of bioethical models by replacing and modernizing old non-coevolutive

approaches, values, attitudes in the relationship of human and nature with those which are in tied concordance with fundamental purpose of humankind survival.

HEALTH AND DISEASE AS EMERGENT PHENOMENA

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The concept of health remains enigmatic. At one end of the spectrum, naturalistic views such as that of Christopher Boorse take health as the absence of disease, which is just the reduction of species-typical biological functions contributing to survival and reproduction. At the other end of the spectrum, holistic views like the World Health Organization's definition of health encompass not only biological but also psychological, social and cultural elements. Here, I lay the foundation for a new analysis of health. My understanding of health is largely inspired by the work of Georges Canguilhem, who argues that health is not a state but an activity. Health is not the absence of disease but the ability to live with pathology and set new biological norms in response to the challenges of the environment and of disease to the body. Health is thus relative to a particular context and is value-laden. This does not imply that health is merely subjective, however, for Canguilhem provides a biological and ontological understanding of value.

My task here is to show how such a complex understanding of health can arise. For this I rely on the idea of emergence, a concept that has recently been used extensively in both philosophy and science to explain complex phenomena. Emergent phenomena are usually taken to be irreducible; while they depend upon more basic phenomena, they have a distinct existence that is impossible to predict from knowledge of the more basic phenomena. My claim is that health and disease are emergent phenomena, depending on biological, psychological, social, and perhaps even spiritual aspects of living organisms. For example, the idea of oral health and disease emerges from various factors including the bacterial genesis of dental caries, the link between psychological stress at work and periodontal disease, the association between socio-economic status and dental caries, and even changing expectations about the possibility of retaining one's natural teeth for the entirety of one's life.

This new theory of health looks to recent work on complexity and emergence to transcend the holism-reductionism dichotomy. The idea of emergent health obviously rejects the biological reductionism of the standard biomedical model. While the emergent theory of health may look like a holistic theory, it tries to avoid the seemingly mysterious aspects of holism by recognizing that health, as emergent, is completely dependent on its more fundamental building blocks.

THE ROLE OF ETHICS COMMITTEES AND ETHICS CONSULTATION IN ALLOCATION DECISIONS: A 4-STAGE PROCESS

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Introduction: Decisions about priority setting likely occurs in all health care systems worldwide. So far very little work has been done on the question of what role ethics consultation and ethics committees could or should play in questions of priority setting at the hospital level.

Objectives and Methods: This presentation argues for the need of ethics consultation in priority setting referring to empirical studies about the status quo and the internal structure of bedside rationing. Subsequently, we present and discuss a four-stage process for establishing and conducting ethics consultation in priority setting by systematically referring to core elements of procedural justice (Strech et al. 2010).

Results: Qualitative and quantitative findings show a significant demand for ethics consultation expressed directly by doctors, as well as an additional, indirectly expressed need as indicated by ethically challenging circumstances of inconsistent and structurally disadvantaging priority setting.

Conclusions: With respect to the outlined demand we suggest four stages for establishing and conducting ethics consultation in priority setting: 1) training, 2) identifying actual scarcity-related problems at clinics, 3) supporting decision-making and 4) evaluation. The practical goals of these four stages are (i) to encourage an awareness and understanding of ethical problems in priority setting, (ii) to encourage rationalization before rationing, (iii) to reinforce consistency in inter- and intraindividual decision-making, (iv) to facilitate explicit reflection and justification of the prioritization criteria taken into consideration, (v) to improve internal (in-house) transparency and external transparency, and last but not least (vi) prevent the misuse of the corresponding consulting structures (Strech, D., Hurst, S. and Danis, M. (2010). "The role of ethics committees and ethics consultation in allocation decisions: a 4-stage process." *Med Care* 48(9): 821-6.)

ARE THERE ADVERSE CONSEQUENCES OF QUIZZING DURING INFORMED CONSENT FOR HIV RESEARCH?

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Introduction: While quizzing during informed consent for research to ensure understanding has become commonplace, it is unclear whether the quizzing itself is problematic for potential participants. Yet, participant acceptability and cultural appropriateness of these assessment methods have not been well studied, especially in vulnerable populations who may have had limited formal education, engage in

illegal or stigmatized activities (e.g., drug use, sex work) or otherwise be unaccustomed to being quizzed. In this study, we address this issue in a multinational HIV prevention research trial enrolling injection drug users in China and Thailand.

Methods: Enrollment procedures included an informed consent comprehension quiz. An informed consent survey (ICS) followed.

Results: 525 participants completed the ICS (Heng County, China=255, Xinjiang, China=229, Chiang Mai, Thailand=41). Mean age was 33 and mean educational level was 8 yrs. While quizzing was felt to be a good way to determine if a person understands the nature of clinical trial participation (97%) and participants did not generally find the quiz to be problematic, minorities of respondents felt pressured (6%); anxious (5%); bored (5%); minded (5%); and did not find the questions easy (13%). In multivariate analysis, lower educational level was associated with not minding the quizzing (6-10 yrs versus 0-5 yrs: OR=0.27, p=0.03; more than 11 yrs versus 0-5 yrs: OR=0.18, p=0.03). There were also site differences (Heng County versus Xinjiang) in feeling anxious (OR=0.07; p<0.01), not minding (OR=0.26; p=0.03), being bored (OR=0.25; p=0.01), and not finding the questions easy (OR=0.10; p<0.01).

Conclusions: Quizzing during the informed consent process can be problematic for a minority of participants. These problems may be associated with the setting in which research takes place and educational level. While at first glance quizzing seems to provide a relatively easy means of appearing to fulfill this objective, there remains a surprisingly difficult set of questions which remain regarding quizzing; these include what constitutes adequate understanding, what aspects of the study are important to understand, and what effects will this quizzing have on potential participants, including not only their attitudes, but also on their willingness to participate, trust, and adherence to study requirements. These issues warrant rigorous attention, both conceptually and empirically. In the meantime, formative research should be conducted in settings in which quizzing is being proposed to evaluate comprehension during the informed consent process so that alternative means for ensuring comprehension might be developed and implemented in settings where quizzing may be problematic.

'OUT OF THE FRYING PAN INTO THE FIRE'

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NICE, Legitimacy and Value-Based Pricing in the English National Health Service'. The paper would consider the proposed reconfiguration of NICE's role as part of a process of value-based pricing of health technologies, with particular reference to the implications which this may have upon the legitimacy and

accountability of the Institute (drawing comparisons with institutions elsewhere, such as Pharmac (New Zealand) and PBAC (Australia)).

DOES AMPHETAMINE ENHANCE YOUR HEALTH? ON THE DISTINCTION BETWEEN HEALTH AND “HEALTH-LIKE” ENHANCEMENTS

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It seems that we all have a moral obligation to restore, preserve and enhance health, our own and that of others, e.g. that of our children or parents. It is also an imperative within health care, medicine and public health, to support and enhance people's health. Health is, furthermore, thought to be a human right. In its most ambitious formulation health is not only "a fundamental human right", but "the attainment of the highest possible level of health" is "a most important worldwide social goal" (WHO 1986). These ethical imperatives make it important to discuss what health is, and what kinds of enhancement are increases in health and what kinds are not.

This paper presents different attempts to draw a demarcation line between processes and states that we believe should belong to the concept of health, and processes and states which we believe should not belong to it. Since all we can expect to produce is a nominal definition, some initial criteria for the explication of health are presented. On the basis of these criteria, a holistic, pluralistic theory is suggested. The theory defines health in terms of basic abilities and well-being. A distinction is also made between manifest health, i.e. the ability and well-being here and now, and basic or fundamental health, i.e. the internal foundations for manifest health. Given these conceptual starting points, the remainder of the paper discusses various ways of trying to differentiate between enhancement that is an increase in (the various aspects of) health, and enhancement that is not, e.g. if there is a distinction between reducing ill health, and promoting positive health, or between "normal" and "supernormal" enhancement. It also discusses if the means used matter, e.g. if wheel-chairs, implants, medicine, narcotics, or genetic manipulation enhance health, if they only compensate for the lack of it, or if they enhance something else, such as non-health-related abilities, capacities or competences. Finally, the paper makes some suggestions towards distinguishing substances that are health-enhancing and those that are non-health-enhancing, e.g. those that are normal to humans, or normal in the culture, those which individuals need in order to live and to flourish, and those that can be tolerated in the long run by the human body and mind.

GLOBAL JUSTICE IN THE AGE OF INTELLECTUAL PROPERTY: THE RIGHT TO HEALTH AND ACCESS TO MEDICINES

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Since slightly more than a decade, the recognition has become increasingly common that there may exist a deep conflict between intellectual property rights and basic human rights. Any system for the protection of intellectual property rights (IPRs), as DeCamp points out, has three main kinds of distributive effects. It will determine or influence: (a) the types of objects that will be developed and for which IPRs will be sought; (b) the differential access various people will have to these objects; (c) the distribution of the IPRs themselves among various actors.

What this means to the area of pharmaceutical research is that many urgently needed medicines will not be developed at all, that the existing medicines will not be suitable for countries with a precarious health infrastructure or not target the disease variety that is prevalent in poorer regions. Such effects are commonly captured under the rubric of the "10/90 gap" in biomedical research. High prices will also restrict access to medicines as well endanger compliance to treatment schemes. IPRs are mainly held by multinational corporations situated in the developed world, which not only raises egalitarian concerns, but also severely limits the possibilities of companies in poorer countries to realize improvements on existing inventions, since they cannot financially afford to secure freedom to operate, which systematically shrinks the number of potential innovators.

All this amounts to an enormous burden for the poor people all over the world and since no institution is willing to assume the responsibility to fulfil the right to health and the corresponding right of access to essential medicines, we have to analyse alternatives to or additions to the actual intellectual property regimes in order to create new incentives to fill in this gap. Proposals like the Global Health Impact Fund as elaborated by Thomas Pogge, among others, or James Love's innovation prizes, are laudable, but do not actively work to alleviate the third problem of distribution. Here models of open science are being taken quite seriously as an addition to the present system of innovation.

MEDICAL DIAGNOSTIC MODELLING: MOVING TOWARDS A MORE ONTOLOGICAL FRAMEWORK

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Among the main purposes of medical diagnosis are to explain illness, predict likely consequences and suggest interventions to improve a patient's outcome. Central to the diagnostic process is the concept of disease as a pernicious, dysfunctional, biological state that threatens health. This medical concept of

disease developed from contagion theory and is based on: typical signs and symptoms, pathological lesion and aetiological agent. By default it has become a template for understanding the majority of health problems. However, while this has led to major successes in dealing with acute and traumatic illnesses, other health problems, mostly falling into the ‘chronic’ category, have not responded so well to this analysis (Greaves, D. (2002). Reflections on a new medical cosmology. *Journal of Medical Ethics*, 28, 81-85). One particularly significant group—because it utilises up to 50% of General Practitioners’ time—is known as ‘medically unexplained symptoms’ (MUS), and includes 80% of low back and similar musculoskeletal problems. Until recently these have been dismissed as psychosomatic, but now it is suggested that they should be taken more seriously and physicians are being challenged to suggest alternative ways of understanding them.

In this paper, it is suggested that these kinds of problems might respond better to complexity theory in which the cause-effect relationship is understood as an adaptive system consisting of a network of factors resulting in uncertain outcomes rather than a predictable linear process. One such model, termed the *Cynefin Framework*, has been proposed by Dave Snowden. This has the potential to open the way to an ontological rather than epistemological way of understanding illness.

PATIENT OR SCIENCE: DO WE NEED TO CHOOSE?

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Evidence Based Medicine (henceforth EBM) has been criticized for neglecting the patient and preferring positivistic science. Positivism means that scientific proof needs to be interpreted as facts on the world. Moreover, it claims that scientific knowledge only consists of proof (Goldenberg, M.J. On evidence and evidence-based medicine: Lessons from the philosophy of science, *Social Science and Medicine*, 62, 2006: 2621-2632). If EBM is really such an account of medical practice, then we will get a situation whereby we must choose between the individual patient and the hard scientific facts.

We will falsify this statement on the basis of four reasons. (i) The common definition of Sackett et al. takes into account best research evidence *and* clinical expertise *and* patient values (Sackett, D.L., Straus, S., Richardson, S., Rosenberg, W., and Haynes, RB. *Evidence-based medicine: How to practice and teach EBM*. 2e edition, Churchill Livingstone, New York, 2000). Moreover it is not possible in our society that a physician neglects the clinical expertise and patient values. Ethical guidelines and the rising patient empowerment make it very hard for a doctor to deny patient values. (ii) In (Sleigh, 1995) (published in the notorious *The Lancet*) it is argued that by using the incompleteness theorem of Gödel –which is a purely mathematical theorem on basic arithmetic- it can be shown that EBM has “shaky logical

foundations” (Sleigh, J.W. Evidence-based medicine and Kurt Gödel, *The Lancet*, 346, 1995: 1172.). We will show that this statement is based on an incorrect assumption on Gödel; and thus that this argument cannot be taken serious. (iii) Tacit –i.e. implicit- knowledge is an important source of knowledge in clinical practice. This kind of knowledge can/will not be made explicit; ergo doing medicine is more than just research evidence and proofs. Diagnosing without tacit knowledge would probably raise the amount of misdiagnoses. An experiment by Montgomery shows that young practitioners know that the more experienced/older physician, the better they become (Montgomery, K. *How Doctors Think. Clinical Judgment and the Practice of Medicine*. Oxford University Press, New York, 2006). (iv) The last argument is based on social psychology insights. A person who has a limited time frame will use short cuts and a person who is experienced in something will also use shortcuts to obtain her/his goal. This implicates that a physician will often use knowledge not directly based on proof or research evidence. The example of an ER doctor, who has only a very limited amount of time to decide which diagnosis is the right one, will be discussed.

These four arguments show two aspects of EBM. 1. EBM is often being misunderstood. It is not a positivistic approach to science without considering the patient. 2. If we accept argument 1, then it is not necessary to choose between the patient and science.

INFORMED CONSENT IS KILLING TRUST IN MEDICAL PRACTICE

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Informed consent has gained increasing salience within the health care field (O. Corrigan 2003). The need to secure a patient’s fully-informed consent prior to medical intervention for treatment or research purposes is increasingly heralded because it counteracts the potential danger of paternalistic practices. The assumption underpinning the implementation of informed consent is that doing so will protect the rights and welfare of individuals by offering them the opportunity to make free and informed choices. In general the informed consent process is depicted as an antidote to counter medical paternalism and as such, a polar opposition has been established with the empowered, informed, autonomous decision-making patient or research participant at one end and an almighty paternalistic authority at the other. The current theoretical underpinnings of the principle of informed consent have largely been derived from bioethics and, especially, research ethics. In particular, the growth of principlism within this field has proved very attractive for governmental regulatory mechanisms. The increasing centrality awarded to the moral dictate ‘respect for autonomy’ has been observed by sociologist and bioethicist Paul Wolpe (1998) and others who note that in the USA autonomy has triumphed in relation to other bioethical principles,

having become progressively more important over time. The dominance of autonomy in bioethics is also a reflection of the increasing centrality being awarded to individualism within Western liberalism more generally. Inside the bioethical frame, autonomy is presented as the ability to act freely without constraint or coercion. To quote from Tom Beauchamp and James 'Principles of Biomedical Ethics': ". . . the core idea of personal autonomy is an extension of political self-rule to self-governance by the individual: personal rule of the self while remaining free from both controlling interferences by others and personal limitations such as inadequate understanding, that prevent meaningful choice" (Beauchamp and Childress 1989: 68). As critics of this form of bioethics have argued, such an understanding of informed consent is premised largely on the autonomous individual and his or her rights, with little or no conception of the social aspects of the world the person giving the informed consent lives in. But this is only the consequence on one side. There is also an impact on how medical practitioners experience their own profession. Before, medicine functioned in a different way. The health care professional was not the adversary but the person one trusts. One goes to the doctor not because one has negotiated well but because one has 'faith' in his or her skills and knowledge.

Due to the emphasis on informed consent in the recent past the attitude of the health care professionals may change radically. It is the opinion of this contribution that health care professionals regard the informed consent more and more as a save guard for themselves and not for the patient or the research participant. Because the person, be it a patient or a research participant, has signed the informed consent form the health care professional feels save. No legal charges can be made. In this way the core element in the relationship between health care professionals and patients is being destroyed: trust.

HEALTH CARE FOR THE UNDOCUMENTED: AN ONTOLOGICAL WAR IN THE US

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The healthcare system in the US has followed a vastly different evolutionary trajectory than in many other parts of the developed world. It appears that the US healthcare system stands poised to do so again. Proposed changes to health care coverage in the US under the Obama administration will theoretically permit all who wish to purchase some form of health care coverage to do so. Those remaining uninsured and hence most likely to utilize social services and emergency health care programs will likely be undocumented residents. In light of changing ideology and evolving practice regarding what constitutes just health care in the US, this presentation will address the remaining moral obligations to provide healthcare services to undocumented residents and their children. This presentation will address

commonly accepted ethical considerations, such as human dignity, against the backdrop of divergent ontological considerations unique to US conceptions and applications of justice.

In order to properly situate the current state of this ethical question in the US, this presentation will briefly outline both key historical periods in the health care delivery system and elucidate the changing societal perceptions of immigrants and undocumented residents during these time periods. The background information provided will trace the normative assumptions which have, thus far, been salient to the evolution of justice or injustice along both the major points of transition in the health care system and the marginalization of immigrants and undocumented residents in the US. Secondly, this presentation will outline several key and currently proposed changes to the US health care system, under the Obama administration. These proposed changes will be discussed in light of the emerging normative assumptions and the tentative consensus in the US regarding what should now constitute a just health care system. The current obstacles and on-going political and personal resentments regarding health care will be addressed. Finally, this presentation will take up the issue of how the proposed changes to the US health care system will or should alter the landscape of health care access for undocumented residents and their children. The presentation will utilize both the secular understandings of US justice obligations as well as relevant socially construed or epistemologically based theological considerations of justice in its analysis of the moral obligation to provide health care to undocumented workers.

MORAL ENTITLEMENTS AND THE CAPABILITY TO BE HEALTHY

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The aim of the paper is to present an argument that every human being has a moral entitlement to a capability to be healthy (CH), and to a level that is commensurate with equal human dignity in the contemporary world. The moral claim is to the capability and not directly to certain 'health outcomes' or particular biological and mental functionings. And, more specifically, the entitlement is to the social bases of the CH. This means that given the four determining factors of health including biological endowments and needs, individual behaviours, physical environment, and social conditions (inclusive of health care), individuals have a moral claim to the practically possible and permissible social interventions into those four determinants in order to produce a CH that is commensurate with equal human dignity in the modern world. There is also a further claim that when something is not immediately socially feasible, the CH gives rise to a claim for social policies that takes steps towards feasibility.

In contrast to theorizing about social justice which makes health and longevity implicit or does not recognize them as concerns at all, a theory or conception of social justice which explicitly recognizes a

moral right to the capability to be healthy as a fundamental value unequivocally asserts the central importance of health and longevity to human beings, and requires social action as well as social vigilance against unjust premature mortality and preventable impairments. Indeed, given the deeply troubling aspect of social arrangements causing premature mortality and preventable impairments, such an entitlement could be foremost a ‘negative’ entitlement that protects people’s health and longevity from socially caused harms. But such an entitlement can also be a ‘positive’ entitlement to certain social arrangements, or social bases, resources, conditions, support, assistance—call it what you wish—that would produce and, promote, or restore a capability to be healthy. Furthermore, as Thomas Pogge argues, in between negative and positive claims, individuals also have ‘intermediate’ claims to remedies for past harms. All of these kinds of claims can follow when what is supposedly a pre-requisite circumstance of justice or what resides implicitly in theories regarding health and longevity is transformed into an explicit moral claim from the start.

The argument for a moral entitlement is ethical but the concepts of a capability to be healthy, the social bases of the capability, and threshold levels of capabilities are not completely ethical ideas; they are also empirically grounded in the natural and social sciences such as biology, epidemiology, sociology, and economics. The moral argument is aligned with relevant empirical facts and theories making it coherent across the health sciences, social sciences, and philosophy. The core argument is that a person’s health is most coherently conceptualized as an assessment of her abilities to be and do things that make up a minimally good, flourishing, and non-humiliating life for a human being in the contemporary world.

AN ETHICS DOCUMENTATION CENTRE FOR BELARUS

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An Ethics Documentation Centre (EDC) has been recently established in International Sakharov Environmental University (ISEU, Minsk, Belarus). EDC focuses on collecting and systematizing of the information on bioethics in Belarus and providing information support to the persons involved in the field. EDC contributes to stronger collaboration of such bodies as National Bioethics Committee, The Republic Center of Examinations and Trials in Health Service, Ministry of Health (BMH), Ministry of Education, Academy of Science, universities and local reviewed ethical committees (RECs) in Belarus. An essential part of EDC establishment is the development of a large database on publications, educational resources, bio-legal documents and information on ethics institutions, experts and events in Belarus. The database developed is supposed to be available for end-users through university website and centralized European portal. A range of reasons for the EDC establishment could be discussed.

Development of Belarusian bioethics has been started since 1998 with the advent of local RECs. Today there're more than 50 institutions that operate with different aspects of bioethics in Belarus. Despite the number of ethics institutions in Belarus seems to be sufficient the following problems could be identified: 1) lack of information on the institutions mentioned activities profiles; 2) their activities are not effectively coordinated; 3) their hierarchical relationships are unclear. Establishment of the EDC will serve to develop stronger collaboration between existing institutions and initiatives in the field of bioethics in Belarus.

Since the year 2000, when the 1st International conference was held in Minsk, Belarusian specialists have got a strong support from international organizations. Since 2006 three projects have been supported by the UNESCO Office in Moscow and included three different aspects of ethical enlightenment in Belarus: training teachers, advanced education of medical specialists and researchers and informing the community. As a result a range of educational programs (for pupils, students, medical specialists, researchers, teachers, journalists and administrative officials) have been developed. In 2003 the 1st text-book in bioethics was published in Belarus. More than 10 educational resources have been published in Belarus up-to-day. Including these educational programs and manuals into EDC's database will make them available for end-users in other counties.

Being non-EU country Belarus can't directly implement European and international bio-legal documents into its legislation. The most cases of researches involving humans and relationships between patients and physicians in Belarus are regulated by orders of BMH written on the base of ratified international documents and Belarusian legislation. In order to represent Belarusian legislation in the field and make the search of the bio-legal documents easier selective documents have been included into EDC's database.

Thus, it's essential for the further development of Belarusian bioethics to systemize the existing experience, especially concerning data on ethics institutions and experts, educational programs and manuals, publications and conference materials, legal documents and information on events, that supposed to be the main objective of the EDC established.

IRREGULARITIES IN CLINICAL RESEARCH IN POLAND ACCORDING TO NIK REPORTS

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The Supreme Audit Office of Poland (*Najwyższa Izba Kontroli*, or NIK), which is a member of EUROSAI (European Organisation of Supreme Audit Institutions), is the supreme body of audit, subordinated to the *Sejm* (Lower chamber of the Polish Parliament) and acts in accordance with the principle of collegiate responsibility. NIK controls the execution of the state budget, as well as quality of management and possible irregularities of public institutions. With decades of activities NIK has gained a high reputation.

In my presentation I would like to focus on two NIK reports published in 2010 and 2011. The first one was devoted to financial support by pharmaceutical companies assigned to performance clinical research. The second one was devoted to quality of supervision of clinical trials in 13 clinical hospitals. In both reports many irregularities was detected.

This presentation aims to describe these infringements and errors and to raise the question whether they are based on structural problems of clinical trials regulations. Many Polish regulations of clinical trials based on EU regulations (UE 2001/20/EC, UE 2005/28/EC (2005) directives were implemented), therefore I would like to prepare more general conclusion.

PRIORITY SETTING IN RENAL TRANSPLANTATION

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Background: Kidney transplantation is the established treatment of choice for end-stage renal disease; it increases survival, and quality of life, while being more cost effective than alternative treatments. It is, however, limited by the scarcity of kidneys. The aim of this paper was to investigate the fairness and legitimacy of the priority setting process underpinning access to kidney transplantation in Sweden using the accountability for reasonableness ethical framework, a leading paradigm in health policy. To achieve this, two critical stages of the process with significant influence on access to transplantation were examined: (1) assessment for transplant candidacy, and (2) allocation of kidneys from deceased donors.

Methods: Semi-structured interviews were the main source of data collection. Fifteen Interviews were conducted with participants from all transplant centers and included transplant surgeons, nephrologists, and transplant coordinators for a comprehensive depiction of the priority setting process in kidney transplantation across Sweden. Thematic analysis was used in the analysis of interview transcripts.

Results and Discussion: Decision-making at both the assessment and allocation stages is based on clusters of factors that belong to one or other of three levels: patient, professional, and the institutional levels. The factors appeal to values such as maximization of benefit, favoring the worst off, and equal treatment, which are traded off.

Conclusions: Overall, we believe that the priority setting process for kidney transplantation in Sweden can be considered fair and legitimate. However there is room for improvement. The presentation will highlight both best practices as well as areas for improvement in priority setting process for kidney transplantation in Sweden with reference to the accountability for reasonableness ethical framework.

HEALTH CARE FOR UNDOCUMENTED MIGRANTS IN EUROPE AND THE US: A BIOETHICS PERSPECTIVE

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The International Organization for Migration declares migration as "one of the defining global issues of the early twenty-first century, as more and more people are on the move today than at any other point in human history" (International Organisation for Migration: <http://www.iom.int/jahia/Jahia/about-migration/lang/en>) Climate change, economic pressure, trade liberalization and political instability are listed as some of the reasons for migration. At present, European countries are expecting big numbers of migrants from North African countries due to the ongoing political and economic change. Despite the ethical urgency of questions regarding health care for immigrants, this area is still no standard topic for bioethicists. However, ethical discussions with subsequent ethically sound health care policy are required in this area.

In my presentation I will 1) give an introduction into ethically relevant areas related to immigration, health care and ethics and focus on health care for undocumented migrants. I will 2) describe the situation of undocumented migrants in some selected European countries and in the US. I will explain the different legal backgrounds and give an overview over the situation as it is described in media and in academic research. Subsequently I will 3) identify the core ethical problems related to resource allocation, just health care and the question of prioritization of national interests vs. responsibility towards all global citizens. To conclude I will 4) sketch some principles that should be respected when managing health care for undocumented migrants.

HUMAN DIGNITY AND RESPONSIBILITY: A LEVINASIAN CHALLENGE TO SWEDISH PRIORITY-SETTING DISCOURSES

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As many other countries, Sweden has an ethical platform for priority-setting in health care. The platform consists of four principles: the principles of (respect for) human dignity, cost-effectiveness, needs and solidarity. The platform has come under new scrutiny during recent years (Prioriteringscentrum 2007, Sahlin 2008, SMER 2009).

This paper focuses on one suggestion that has been made in this debate: that one more principle may be added – the principle of responsibility. According to this principle, we should respect others by seeing them as responsible for their actions and for consequences of their actions (while also taking into account that the individual's ability to take such responsibility will vary). This principle, it is also suggested, can

be derived from the principle of respect for human dignity. Furthermore, it is used as a starting-point for a discussion about the individual's responsibility for making sure that she or he receives the care that is called for and, in some cases, finances it (see Prioriteringscentrum 2007:133-135).

The paper is divided in two parts. It starts by discussing two possible interpretations of human dignity that has been suggested in the Swedish debate on ethics and priority-setting. It examines whether the principle of respect for human dignity – in either of these two interpretations – can imply or motivate a concern with self-responsibility as suggested above. It also broadens the discussion and suggests a line of reasoning according to which respect for human dignity can imply a concern with responsibility for others. The second part turns to the reasoning of Emmanuel Levinas. Levinas stated, repeatedly by approvingly quoting Dostojevski, that the self is always responsible for the Other, always more responsible for the Other than anyone else, and that the self should not be concerned with reciprocity in ethics. His ethics, one may say, emphasizes a far-reaching ethical asymmetry.

This may make a Levinasian ethics appear as a strange starting-point for a discussion of human dignity and responsibility in priority-setting in health care. My aim, however, is to examine the potential of Levinas' work. Can it help us rethink the concepts of human dignity and responsibility? What would the implication of a principle of respect for human dignity be, in the context of an ethical platform for priority-setting in health care, if we would start with a Levinas-inspired conception of human dignity?

BIOMATERIALS - FROM UTOPIA TO SCIENCE

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New developments in contemporary technosciences tend to blur the distinctions between prevention, therapy and enhancement. In my paper, I will focus on a particular development, namely viral biomaterials. Viral life forms can be genetically modified (their genomes can be rewritten) in such a manner that they may be inserted in human bodies in order to produce substances at specific sites such as hormones (testosterone), neurotransmitters (dopamine), enzymes (insuline) or bone and muscle tissue. Notably, certain target groups such as top athletes, soldiers or patients suffering from degenerative diseases may become the pioneers serving as test-beds for novel applications. The same technologies can be used for various purposes: therapy, prevention and enhancement. I will report results of collaboration of my own group with experts in synthetic biology involved in viral biomaterials research. My analysis entails a number of philosophical and ethical issues ranging from "biomimesis" (the tendency of novel materials and technologies to mimic nature in order to optimise prospects for embedding in natural systems) and ethical issues concerning containment and human enhancement.

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