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Diversity and Bioethics

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ABSTRACTS

Who belongs to us? The right to advanced medical interventions among non-citizens in Sweden

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Sweden has received the highest number of immigrants per capita in Europe. During 2015 around 163 000 immigrants reached Sweden. Most of these, like those arriving before and after, have by now been awarded permanent residence, but some have been expelled, some remain in the country without permission, some await final decision – and there is also an unknown number of persons living in a shadow society while not registered as immigrants and hence in no files. Different numbers have been proposed for how many persons there are in these respective categories, but their exact numbers remain unknown.
Since some years, the access to the Swedish health care system has been regulated by directives where the crucial formulation is that persons who are in Sweden but do not have permanent residence here have a right to, in Swedish, "vård som inte kan anstå" – "care which cannot be postponed". This is a somewhat cryptic formulation, very hard to handle in practice. Hence clinicians interpret differently, resulting in sometimes strong reactions in public media.
On request from a number of thoracic surgeons dealing with heart transplantation, the Swedish "State Board for Medical Ethics", Smer, during 2020 launched a project to explore the ethical basis of such decisions in order to provide some recommendation. Smer:s reports should be seen as exactly recommendations and the board has no legal capacity to initiate changes in the guidelines for prioritization of advanced medical interventions – but they may still be influential.
Smer presented a report in the spring of 2021 where the conclusion, in very short, was that even very advanced and very resource consuming medical care should be given to persons in Sweden, irrespective of their legal status. This means that persons without permanent residency, persons who are awaiting or keeping away from a decision to leave the country, or so called "paperless", who are not registered at all, should be prioritized on the same premises as Swedish citizens and persons who have permanent residency.
I will discuss this conclusion and point to a number of aspects which I think that Smer too quickly brushes aside as well some some weaknesses in their analysis. This dilemma illuminates with harsh sharpness how exceedingly difficult priority setting may be in a world of nation states where persons increasingly migrate over borders.

(Too much) technological optimism (or pessimism) constructs simplistic theoretical foundations

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Bioethics scholars are often employed to grasp ethical, legal, and social aspects of new (bio)technologies. However, these aspects are not fully equipped with conceptual tools to ask whether a technology is a good answer to the problems it is supposed to solve; what sort of values does a technological answer promote; and how the knowledge on which the technology is build is constructed in the first place. These are questions that the conceptual framework in science and technology studies are comfortable with. Narrowing down the 'building site' to ELSI questions of a technology, instead of questioning the argumentative line of the priorities and values embedded in technology *as an answer* can be seen as conforming to 'business as usual' without posing any threat to dominant interests.

A legitimizing approach to new technological initiatives contributes to a promissory landscape. Biotechnologies are framed with hopes and promises about a future in which the technology has fixed a certain problem or need. Such promises are not neutral: even though the expectations concern the future, they generate change in the present political-economic context by mobilizing resources and directing discussion to support technology *as an answer*. The hype takes away attention and prioritization from sociopolitical and other solutions that might be even more important to the original challenge. Furthermore, aiming for technology-oriented solutions enforces discrimination. An ELSI-approach can routinely point, for example, that a technology in question needs attention concerning accessibility. However, there is less vocabulary to ask whether the resources used to that technology could be spent better elsewhere in more mundane political spheres. Technological answers are often best for those who are privileged with their other areas of life, such as socioeconomic position and social determinants of health.

Of course, sometimes a technology is an impeccable answer. Bioethics discussion on a 'desirability' of a technology are often framed to find out whether a discussant is committed to (liberal) technological optimism or (conservative) pessimism. I argue that this is insufficient. In this paper, I call for a closer theoretical cooperation between conceptual frameworks of bioethics and science and technology studies.

Increasing participation of diverse public stakeholders in biomedical research oversight

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Inclusion of community, patient, and research participant stakeholders (henceforth "stakeholders") in the design, implementation, and dissemination of biomedical and other health-related research can enhance the social value, scientific validity, and clinical utility of research results. Stakeholder engagement in research is not only an ethical imperative in its own right; it is critical to achieving other important ethical goals such as informed, voluntary consent; diverse, representative participants; and ensuring that research is responsive to the needs of vulnerable communities. While stakeholder engagement is now widely incorporated into individual research projects through approaches such as community-based participatory research, participatory action research, and citizen science, it is not well-integrated into ethical and regulatory oversight of research in the U.S.

While some countries have detailed and robust requirements for the participation of non-scientists on research ethics committees (RECs), U.S. federal regulations (45 CFR 46.107) require the inclusion of only one institutional review board (IRB) member who is not a scientist and one member who is not affiliated with the research institution. However, evidence suggests that the typical practice of including 1 or 2 non-affiliated, non-scientist IRB members does not adequately meet the intended goals of bringing a perspective sensitive to community attitudes or diverse membership; "community representatives" are overwhelmingly white, educated, and supportive of research, calling into question the degree to which they can represent the interests of diverse stakeholders. Other stakeholder engagement activities at the institutional and research project levels, such as community advisory boards and engagement studios, can provide valuable input on ethical issues, but the extent to which input from public stakeholders is directed to or considered during IRB review is unknown. Increased collaboration between

human research protections programs (HRPPs) and institution-level community engagement activities could bring stakeholder perspectives to bear on research ethics oversight.
In the proposed presentation, I will first outline a justification for the increased inclusion of diverse, public stakeholder perspectives in the ethical oversight of biomedical and other health-related research. Then, I will compare how several different countries include stakeholder perspectives in research ethics oversight, for example, through requirements for public members or through public outreach efforts. Lastly, I will describe and present findings from a mixed methods, empirical bioethics research study using qualitative interviews with IRB leaders and a Delphi panel of diverse stakeholders to identify strategies and resources for increasing stakeholder engagement in research ethics oversight.

Trachea transplants and the regulation of unproven methods in clinical innovation
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A recent attempt to develop and transplant synthetic human tracheas resulted in several fatalities and charges of scientific misconduct. The subsequent scandal led the Karolinska University Hospital in Stockholm, Sweden, where some of the transplant operations took place, to draw up restrictive guidelines for unproven methods. This is contrasted with recent work, which argues for less restrictive regulation of unproven methods and clinical innovation. This study highlights the distinction between research and clinical practice and to what extent it matters morally. Considering the common view, that the use of unproven methods outside of clinical trials is not research and that the dominating moral principles in this context are respect for autonomy (of both patient and clinician) and clinical freedom, I argue that even if clinical innovation is not research, it should be similarly regulated, and, in particular where the unproven method is invasive or poses significant burden or risk to the patient, its use must be reviewed by a research ethics committee or a similar independent, institutional body. It is of utmost importance to produce regulation of clinical innovation that not only aims to protect patients while promoting innovation, but that is also robustly implemented and that provides careful and trustworthy oversight mechanisms.

Deliberation Processes and Accountability Practices in Bioethics
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Deliberative processes in bioethics are most often discussed in relation to attempts to engage citizens in debates about bioethical policies. This participation has taken several forms, such as citizen panels, citizen juries, deliberative polling, or mini publics where representative groups of citizens are selected for deliberation and consultation. These can be interesting and valuable exercises in democracy that exemplify serious attempts to realize democratic values that are often thwarted and neglected in the aggregative and manipulative practices of democracy. However, these attempts to facilitate deliberative processes in conditions of reciprocity which minimize distortion, ignorance, and domination, are fraught with problems. These problems relate to things like power asymmetry of the participants who face an already determined agenda, limited inclusion, and lack of influence on real policy making. For this reason, such deliberative exercises are often criticized for not serving their democratic role; they can become diplomatic ways to ensure a docile population through managed consultation and consent. In this paper it is argued that there are other ways to introduce deliberative processes of relevance

for bioethics that have been neglected in the literature. This draws upon Habermas' (1998) statement that "the success of deliberative politics depends not on a collectively acting citizenry but on the institutionalization of the corresponding procedures and conditions of communication". This directs attention to the deliberative processes that flow through both the formal political bodies and the informal networks of the public sphere. As Simone Chambers (2003) argues, this also implies that accountability rather than consent becomes the "conceptual core of legitimacy". From the point of bioethics, the focus should, therefore, be on the quality of reasons and arguments provided when policy is justified. This calls for critical reflection on the conditions for democratic legitimacy and practices of accountability in relation to bioethical policy making.

'It is highly unlikely that your child is healthy'[1] - New horizons of parental responsibility in the context of non-invasive prenatal testing

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The first discoveries of cell-free DNA fragments of the unborn child in the blood of pregnant women led to a redefinition of prenatal diagnosis. While first non-invasive prenatal tests (NIPTs) were aimed solely at detecting trisomy 21, there are now sequencing techniques on the market that analyse the entire genome of the unborn child. During these tests, data is also collected, whose clinical relevance to the life of the future child cannot be estimated.
Such new testing options open up new corridors of decision-making and responsibility to future parents, starting in early pregnancy and continuing into the post-birth period. In extreme cases, they lead to the conflict of having to decide whether to terminate or continue the pregnancy. These decisions are not always based on confirmed knowledge, but on probabilities and prognoses.
Germany decided on NIPTs being covered by statutory health insurance in September 2019 [1]. The decision of the Joint Federal Committee (G-BA) was preceded by a three-year procedure to assess the applied methods. This procedure was observed critically by the public and, in particular, by associations working for people with special needs [2]. The implementation of the decision is still subject to approval[2] and is not expected to be completed before the end of 2020. Unlike Switzerland, Denmark and Great Britain, no specific risk threshold will be defined for Germany. It will be up to the respective medical practitioner to conclude whether a pregnancy has "special monitoring needs" [1].
In Switzerland the costs of non-invasive prenatal tests for trisomies 21, 18 and 13 have been refinanced by the mandatory health insurance since July 2015 [3]. The threshold is defined as a risk of 1:1000 [3]. Belgium, Denmark and Great Britain followed Switzerland with similar models. In 2017, the Netherlands implemented nationwide NIPTs through the TRIDENT-2 study, funded by the Ministry of Health with 26 million Euros.
Against the background of this multinational development, the paper explores the impact of the new technology. It highlights the tension between knowledge production, knowledge interpretation and dimensions of responsibility. It also investigates indications that these new technologies, which were meant to solve problems, are creating new problems [4, 5, 6]. In the sense of "critical thinking" [7], the paper analyses what appears to be "robust knowledge" [7] and examines it for uncertainties and ambiguities. In a final step, it outlines future scenarios of parental "obligation dimensions" [8] by referring to bioethical discourse lines and contrasts them with the plea for a "beneficence in utero" [9].

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[1]See also Baldus 2020: „Es ist sehr unwahrscheinlich, dass Ihr Kind gesund ist“ Dilemmata und Risiken im Kontext pränataler Diagnostik. In: Bioethica Forum, Swiss Journal of Biomedical Ethics. Issue “Disability and Ethics” (accepted).
[2] Inspection and approval by the Federal Ministry of Health and publication in the Federal Gazette are still pending. In addition, it is necessary to prepare insurance information, which is not expected before the end of 2020.

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“As if weights were hanging on my arms and legs” - Long-Term Effects of COVID-19 Infections in Children and Adolescents

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COVID-19 causes long-term issues in Children and Adolescents. The burden of disease is not yet established and data relating to prevalence, symptoms, duration and disease-course are highly inconsistent. Many symptoms associated with Long-COVID are non-specific and occur in the context of other diseases and psychosocial stress, exacerbated by lock-downs, school closures and social distancing. Differentiating Long-COVID symptoms from psychosocial stressors in the context of the COVID-19 pandemic is challenging (Siebte Stellungnahme des ExpertInnenrates der Bundesregierung 2022).
According to Zimmermann et al. (2022), Long-COVID prevalence estimates range from 0.8-13.3% in studies with control groups. Studies without control-groups report prevalence between 7.9% and 58.1% (Zimmermann et al. 2022). This broad range is largely attributed to variances in research design, case inclusions and research definition. A common research definition consensus has only recently been established (Stephenson 2022).

The Scientific understanding of Long-COVID remains limited. Cases of severely affected young patients exist (Vilser, cit. by Gebhardt 2022) and require improved access to healthcare and therapy. Large sample size cohort studies (Borch et al. 2022, Kikkenborg Berg et al. 2022) report patients endure substantial issues for months following COVID-19 infection. Many are unable to attend school for prolonged periods, are disconnected from friends and peers, feel estranged from their bodies and experience psychological problems. “As if weights were hanging on my arms and legs”, reports one 16-years old girl (Vilser 2022). She is one of hundreds of young patients visiting the first Long-COVID outpatient clinic for children in Germany, located at Jena University Hospital.

Case studies demonstrate considerable challenges experienced by the family unit. Parents are required to rearrange routines, day-care, and work. The dearth of knowledge relating to prognosis and recovery causes a large emotional burden (Müller 2022).

Many countries have installed outpatient clinics. Waiting lists are long and families report a requirement for increased support. Self-help groups such as Long Covid Kids (https://www.longCovidkids.org/) develop online resources to bridge this gap.

Medical, educational and social services require a cohesive approach to manage these children (Baldus, submitted). Schools can assist during periods of absence and offer individual educational plans after return. In 2021, The USA subsumed Long-COVID under Section 504 and the so-called “Individuals with Disabilities Education Act” (IDEA) (United States Department of Education 2021). Similar amendments exist in other countries. The goal should be to give the support needed for children to find their way back into a life without the feeling “as if weights were hanging on my arms and legs”.

The workshop will address these questions. Initial results from the interdisciplinary research project “LongCOCid” at Jena University will highlight psychosocial aspects. The presentation will include data from qualitative interviews with affected families with a focus on ethical principles in healthcare and education.

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Doctor-patient relationship and its evolution: ethical implication of modern technologies

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Doctor-patient relationship is affected by fast development of new technologies such as direct-to-consumer genetic testing (DTC GT), artificial intelligence (AI), mHealth (mobile health applications (apps)), and electronic health records (HER). These technologies allow to individualize treatment modalities, enable patient to participate in decision-making process and may be viewed from the perspective of predictive, preventive and personalized medicine (PPPM). The PPPM marks a paradigmatic change in traditional understanding of healthcare and highlights the increasing role of personal responsibility for health. Since the second half of the XXth century the responsibility for patient's health has been seen as a collective endeavour between physician and patient and the model of shared decision making has been a desirable aim. We explore how the shared decision-making model is affected by the emerging new technologies and what possible risks for the patients might be overlooked. We argue that due to the impact of these technologies the role of physician has been marginalized and the bigger part of responsibility in clinical decision making now rests on patients, creating new areas for concern. In the case of DTC GT and apps, a consumer using the data provided by devices, is the one who can initiate the process of treatment. Should consumers be considered competent enough to deal with attainable genetic information or information by apps? We ask whether the emphasis on patient autonomy and his right to choose in these situations might overshadow the dangers and possible harms that can be mitigated if physicians are involved? It remains unclear whether physician still is responsible for patient's health or only patient himself. On the other hand, the mobile apps can support a physician in monitoring patients during visits. In case of AI, clinical decision making is further complicated as shared decision making model is supplemented by the third party (AI) and there is a question who makes these decisions: physician, patient or AI and on which basis? In all these cases the shared decision making model seems to be transformed, as it seems that the physician, who has a relevant knowledge and ability to explain complicated medical information for the patient, becomes less important. To understand these changes and their implications, we apply a theoretical framework, which is focused on shared decision making, the PPPM and increasing importance of patient autonomy, which is facilitated by the new technologies. In order to properly address these challenges new legal and ethical framework involving not only physicians and patients but also technology developers seem to be needed.

A principled ethical approach to intersex paediatric surgeries

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Surgery for intersex infants should be delayed until individuals are able to decide for themselves, except where it is a medical necessity. In an ideal world, this single principle would suffice and such surgeries could be totally prohibited. Unfortunately, in some places, intersex neonates are at risk of being abandoned, mutilated or killed. As long as intersex persons are at such high risk in some places, any ethical guidelines for intersex surgeries will need to take these extreme risks of harm into account.

I argue for five basic principles that ought to inform ethics guidelines for intersex paediatric surgeries. I propose a set of principles that do not completely prohibit surgery, but only allow it where a strong case can be made for its necessity, in the best interests of the child, and where there is some kind of oversight to prevent misuse.

Principle one is that interventions as drastic as these surgeries should only be performed when there is strong evidence that they are beneficial and not harmful. The second principle is that in surgeries should normally only be performed in cases of true medical necessity. Principle three is that surgeries should normally be delayed until such time as the intersex person is mature enough to assent to treatment or decide against it. Principle four is that conventional ethical requirements regarding veracity apply equally to intersex children as to anyone else. The final principle is that where physicians or parents think that surgery is in the best interests of the child, the burden of proof lies with them.

It is hoped that these principles might help medical teams and parents make better decisions about intersex surgeries on children, and they would make such surgeries very rare, if they happen at all.

Access to healthcare for diverse patients: National peculiarities in Poland

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In Poland, equality in healthcare is enshrined in the constitutional principles of equality and non-discrimination, along with the principle of equal access to healthcare services. It is also grounded in the EU primary law (the Treaties and the European Charter of Fundamental Rights). However, concerning healthcare, the impact of the EU regulations is relatively limited, as this area belongs mainly to the Member States competences (Article 168, TFEU). The grounds of potential discrimination concerned here will be a) race and ethnicity, b) religion and belief, and c) gender identity and sexual orientation, following the research conducted in the scope of the project *Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe*.

Discrimination on the grounds of race and ethnicity in healthcare is prohibited by the Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin. This Directive has been transposed into the Polish national legislation by the Act of 3 December 2010 on the implementation of some EU regulations regarding equal treatment, with nationality being added to the list of protected grounds. Discrimination on the grounds of religion, belief, gender identity and sexual orientation in healthcare is not yet addressed by the EU directives. Although the Member states can introduce such legislations on their own, Poland has not done it. However, access to healthcare for persons of aforementioned features is addressed by numerous national legal acts,

which create a complex yet non-systemic set of legal peculiarities, impacting access to healthcare for persons of diverse features in various ways.
Access to healthcare for persons of diverse national and ethnic origin is addressed not only by the anti-discrimination law. Included into the concept of social integrity it is addressed by the Act of 6 January 2005 on national and ethnic minorities and the regional language. However, this act concerns only recognized ("old") minorities, not migrant communities.
Rights of persons of diverse religion and belief are addressed by numerous legal acts including the Act of 6 November 2008 on Patient's Rights and Patient's Rights Ombudsman (2008) or 13 acts on relations between the state and a particular church or religious association. This creates a complex but not systemic normative framework and results in different levels of protection of rights of members of religious communities.
Contrary, rights of persons of diverse gender identity and sexual orientation in healthcare, not only are not legally protected, but also systemic discrimination could be identified in this area, especially the lack of access to medically assisted procreation. This lack of protection is a part of a broader context of particularly restrictive reproductive health policy in Poland, strengthened with the Constitutional Tribunal judgement K 1/20 on abortion ban, and active anti-LGBT campaign.
In conclusion, the relevance of this set of legal national peculiarities will be evaluated in context of potential adoption of the Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation and later implementation of such a Directive in Poland.

Access to sexual and reproductive health goods and services in Poland

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Discrimination and unequal access to healthcare have many faces in Poland. However, the issue of access to sexual and reproductive health goods and services is of special interest.
In Poland, the legal basis for prevention of discrimination in healthcare can be found in the constitutional principles of equality and non-discrimination, along with the principle of equal access to healthcare services. It is also grounded in the EU law, that is, the Treaties, the European Charter of Fundamental Rights and relevant directives. Yet, the impact of the EU regulations is relatively limited here, as the area of healthcare remains mainly in the hands of the Member States.
On the statutory level, issues of equal treatment, non-discrimination and access to healthcare do not seem to be covered sufficiently in Poland. According to the Constitution, public authorities are obliged to provide equal access to publicly funded healthcare services for all citizens "irrespective of their material situation" (Article 68). Yet, the Act of 27 August 2004 on health care services financed from public funds stipulates that this access is limited to those who have public health insurance or are entitled to it, and to some other groups (e.g. minors, pregnant women, the poor, persons with refugee status). The topic of equal access to healthcare is thus identified in the contexts of financing, waiting lines and geographical proximity, where it is understood mostly in terms of limited resources.
The Act of 3 December 2010 on the implementation of some EU regulations regarding equal treatment addresses i.e. explicitly healthcare. It provides a closed catalogue of grounds, on which unequal treatment is prohibited: gender, race, ethnic origin, nationality, religion, belief, worldview, disability, age and sexual orientation (Article 1). However, in the case of healthcare this catalogue is limited only to race, ethnic origin and nationality (Article 7), with other characteristics being left out.

The aforementioned provisions go along with limited and discriminatory access to sexual and reproductive health goods and services, notably with the restrictive legislation on abortion. Access to sexual and reproductive health goods and services is further limited by the misuses of the conscientious objection law (additionally strengthened by the recent ruling of the Constitutional Tribunal) and various procedural, financial, cultural and other barriers, affecting especially women, LGBTI persons, persons with disabilities, adolescents, persons from socially disadvantaged backgrounds, or migrants. In our presentation we will focus on the following issues:

- the lack of access to safe and legal abortion,
- restricted access to contraception,
- the barriers in access to IVF for heteronormative and LGBTI persons,
- the extremely limited access to sex-reassignment care,
- the obstacles in the access to treatment of sexually transmitted diseases,
- the barriers in access to sexual education,
- the hurdles in the access to non-reproductive sexual health treatments.

Data Access and Use Policies in *All of Us*: Balancing Tensions between Broad Access and Protecting Privacy in "Big Data" Research

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All of Us is gathering a wide variety of data-- derived from electronic health records, participant surveys, biospecimens, and mHealth technologies--from diverse populations, with an emphasis on traditionally underrepresented groups. It is also creating an infrastructure to enable broad accessibility to these data, extending beyond traditional academic researchers to citizen scientists and community-based researchers. This raises important ELSI issues and, in response, the program established the Committee on Access, Privacy, and Security (CAPS), tasked with upholding *All of Us* core values of protecting participant privacy, securing participant data, and building trust through transparency as extended to the establishment and maintenance of the *All of Us* data repository. This session will highlight some of the challenges *All of Us* faces and how the program has worked to define, deliberate over, and mitigate them including, developing a tiered data access framework, reducing risk of participant identifiability, user credentialing, developing a data user code of conduct, establishing requirements for data access and ways to promote public transparency about the.

The Patient Life Empowerment Approach

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The notion of patient empowerment is valued today as both a right and a responsibility. We ask doctors to help the patient participate and the patient to learn about and to manage the disease. However, there continues to be conceptual confusion about what exactly patient empowerment is. This is largely due to the varied interest(s) which have led to different conceptualizations of patient empowerment, should it be from economics, healthcare institutions, or patient associations. Added to this diversity of actors, there are new terms that have sprung up, such as *patient experts* or *patient partners*.[1] These new categories of patients interact with healthcare institutions in new ways, such as teaching future medical students and helping patients learn about their disease. While it may be encouraging to see these new forms of patient participation,

these new categories reflect a special cohort of patients at the service of medical school and/or healthcare institutions, not the everyday patient that most doctors see in their consultation.
Patient empowerment, as a more global term, which can reflect the "everyday patient," remains more promising. As patients, we still have required to *patient*, to support, endure, or even suffer medical exams and often heavy treatment, but at the same time we are now also expected to be empowered to learn about and find ways to live with our diseases. However, for this notion to have any meaning for patients themselves, it will be necessary to build it from patient contributions.
This paper proposes the "patient life empowerment approach." The approach has been developed from the double inspiration of fieldwork with a group of epilepsy patients and philosophical reflections, thanks to Martha Nussbaum's capabilities approach (CA).[2, 3] The patient life empowerment approach considers the patient's life holistically, including in relationships with their families, their doctors, and in society, moving toward a new approach to patient empowerment from the patient's perspective.

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End of life decision-making in ICUs in Croatia what have we found so far?

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This contribution will give an overview of the project entitled VAL-De-END. The main objective of this research project is to conduct a study of decision-making related to the end of his life in intensive care units in Croatia in hospitals at the tertiary level health care (clinics, clinical hospitals, clinical hospital centres) and propose guidelines on the issues. For the purpose of achieving these goals an interdisciplinary research team with experience in similar studies was created. After conducting an analysis of existing guidelines in this are research in focus groups on decision-making, attitudes and values of health staff working in intensive care units at the tertiary level of health care. A cross-section study of attitudes of health workers related to the decision-making at the end life in intensive care units at the tertiary level in Croatia with a specially designed questionnaire was also performed as well as a retrospective analysis of data on patients who have died in the intensive care units at the tertiary level of health care and to analyse therapeutic procedures and decision-making related to end of life and a prospective analysis of the decision-making procedures related to the end of life in intensive care units with specially designed instrument. A research on the representative sample of general population of the Republic Croatia was also performed in order to see what are the attitudes and values related to the decisions at the end life that are dominant in the Croatian population. This conurbation will present main findings of the project. This conurbation will present main findings of the project.

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Recasting 'self-care' as a physician's ethical practice

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Recent evidence suggests that many physicians are paradoxically losing sight of their health because of the cognitive and emotional demands of medical practice. It is frequently suggested in the literature that physicians can address these health issues by improving their own senses of 'self-care', among other things. In this paper, I inquire whether and to what extent 'self-care' should matter to physicians morally in the context of their personal and professional lives. First, I draw on sociological literature and critique the contemporary understanding of 'self-care' as a practice or repertoire of practices. I, then, identify the implications of constructing 'self-care' within a neoliberal social order, in leaving the moral connection between 'self-care' and the physician's work as implied or self-evidently good, and in treating 'self-care' as a *panacea* to serious physician wellness issues. I argue that this construction and understanding of 'self-care' is epistemologically thin and unsatisfying, as it not only reinforces physicians as atomized individuals in western neoliberal healthcare but also neglects their particularities and relations with the 'self' and with the 'other' – both of which are germane to 'good doctoring'. From here, I suggest a more robust account of 'physician self-care' that is not treated as self-evidently good, and that justifies and supports physician practices and particularities. Second, I try to set out the ethical rationale of 'physician self-care' by outlining the link between the traditions of Foucauldian techniques of 'care of the self', narrative ethics, and ethics of care. I argue that all these traditions of 'care' indicate a shared understanding that 'self-care' cannot be deductively judged and solved by applying predetermined norms or rules, but only inductively in a social process that preserves the various dimensions of the complex human experience. To conclude, I suggest that there can be no single universal prescription for 'self-care', but there can be a common moral rationale of 'physician self-care' practices when the ethics of the good life (as an ethic of self-improvement), the experience of 'care', and physician particularities (narratives) are considered.

Ethical Advertising and Moral Bioenhancement

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Suppose that we had access to pharmaceutical interventions that would constitute a moral bioenhancement; if we assumed (as some philosophers have argued) that this would be considered to be a very good thing to have, and that we should prefer that people take it, how should we encourage people to do so? In previous works I have dismissed offering financial incentives and appealing to a sense of duty as options in this endeavour, and so in this presentation I turn instead to consider a seemingly innocuous approach: Advertising the intervention. However, it seems that this approach could be less straightforward and indeed more ethically problematic than as might initially appear.

Given that moral bioenhancements could be said to involve changing what many consider to be a fundamental aspect of a given person's personal identity, this then provides an added dimension of moral weight when considering how to, or even whether we should, advertise such an endeavour – a problem complicated further if the intervention could in fact be medically indicated in certain persons. This presentation explores not only whether an ethical approach to advertising moral bioenhancement interventions (be that as an enhancement or as a treatment) could be possible – but also questions whether advertising the intervention could be considered morally permissible in any instance.

AI as a third pillar in a future patient-physician relationship: the case of breast cancer screening

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The contemporary developments in the algorithmic solutions might bring a revolutionary perspective in healthcare. The current advances in research have demonstrated a certain amount of success in the field of breast cancer screening and diagnosis. Recent three research studies have shown significant progress in this field, the first two did not attract public attention, but the last one published by Google's Deep Mind caught the public's attention significantly. Producing through media, a particular hype presenting as "AI outperformed radiologists" or "AI beats doctors in spotting breast tumours". Leaving aside the hype that media has created among the public, not everyone would agree that the new AI algorithms would bring a specific improvement in the screening process and timely treatment and care without challenges. Their pessimism emerges from the previous methodological flaws, which are tightly related to human involvement in the development and implementation of these algorithmic solutions. Such as partial recruitment of the radiologists not specialised in reading mammograms, or performing a test only on biopsy confirmed outcomes that were contributing to finding more cancers and reducing false positives and false negatives. Although, the experts invest hope that AI would provide a more efficient and better diagnosis which sometimes because of its complexity exceeds human ability they also warn that the algorithms might worsen the pre-existing problems such as overtesting, overdiagnosis, and overtreatment. These existing issues are present in current cancer care ascribed to the physicians' uncertainty to treat everything found as suspicious, which might also transfer implicitly or explicitly in the form of values to the algorithmic solutions.

Furthermore, the AI breast cancer screening tools cannot be isolated from the human aspect that entails from the development to the implementation process close collaboration between professionals specialised in reading mammograms, who will train and later supervise the implementation process. Therefore, the overhyped fears of physicians (radiologists) being replaced by AI screening tools are misleading because they will become their decision-making supporting tools. However, comparing to other technologies used by physicians to facilitate diagnosis and prognosis the AI algorithmic solutions are different, influencing their decision making and changing the existing physician-patient relationship into a new triangular interdependent relationship between physician-AI-patient. This new relationship poses some ethical requirements from the patient perspective tightly related to the transparency, explainability, and trust of the decision made using an algorithm with a preference adjusted to the false positives or false negatives, or patient's autonomy to decide whether she wants the AI to be used in her prognosis or diagnosis. Altogether previously mentioned belonging to the informed decision process will need to be adapted and integrated into the form of informed consent. This new relationship also brings some risks in the way of over-reliance on the AI breast cancer screening tools, leading to underestimation of their skills and expertise by losing their professional self-confidence.

Ethical implications of DAMA: Cross-sectional survey of attitudes and intended behaviour among Lithuanian physicians

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Discharge against medical advice (DAMA) is defined as a decision of a patient to leave the hospital before the treating physician recommended discharge. DAMA raises serious medical (increased risk of readmission and mortality) and economic (higher health care costs) concerns together with sensitive ethical questions. The main ethical dilemma of DAMA is embedded in the conflict between the core principles of medical ethics – the physician's obligation to respect patient autonomy (including patient's right to refuse treatment), and to act in the best interests of a patient (beneficence). In our study, we aimed to investigate the attitudes of Lithuanian physicians towards the patients' right to refuse treatment.

A cross-sectional study of physicians in Lithuania (n=393) using an anonymous online questionnaire was carried out in public sector hospitals in 2020/21. The questionnaire included four cases of patients refusing treatment: (1) elderly man with acute appendicitis and several comorbidities; (2) a young anxious man with acute appendicitis (3) a woman with breast cancer, with chemotherapy need, and (4) a young Jehovah's Witness, who needs surgery but refuses a blood transfusion. Descriptive statistical analysis was conducted using MS Excel, SPSS programs.

Most of the physicians (85%; 95% CI 81.2-88.5%) have faced DAMA cases in their clinical practice, yet their intended behaviour and attitudes did differ. In cases 1 and 2 (acute appendicitis), the majority of physicians would have performed surgery without patients' consent (64.1% (95% CI 59.3-68.7%) and 73.0% (95% CI 68.4-77.3%) respectively). While in the breast cancer case (3) 2/3 (70.5%; 95% CI 65.9-74.8%) of doctors would not apply chemotherapy treatment without consent. The most dichotomized attitude was expressed towards the case of a patient in objection to the treatment due to religious grounds (4) – 52.7% (95% CI 47.1-57.8%) of respondents would have performed blood transfusion without the patient‘s consent. The study revealed that the emergency of the clinical case was related to the physician's intended paternalistic behaviour. Insufficient patient information on intervention and its comprehension was indicated as the main cause for DAMA by 62.9% (95% CI 58.0-67,4%) of physicians indicated. In addition, DAMA was related to fear (57.5%; 95% CI 52.7-62.3%), anxiety (38.9%; 95% CI 34.1-43.8%) and anger (38.4%; 95% CI 33.8-43.5%) among physicians.

The study revealed a diversity of physicians' attitudes and intended behavioural patterns in different cases of DAMA with the highest paternalistic express doctor-patient relationship in most severe clinical conditions. The study proves the relevance of the DAMA problem in the Lithuanian health care context. The findings also give us a suggestion about the potential gaps in physicians' preparedness for DAMA, and a lack of communication skills. There is a clear need for more elaborated legal interpretation of the practical application of patients' right to refuse treatment, also more training and information for the medical community.

Biospecimen Access and Data Use Monitoring: Preventing Harm to Individuals and Communities

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The *All of Us* biorepository provides a rich and unique resource of biological specimens contributed by *All of Us* participants, that can then be used to study a wide range of scientific questions to improve knowledge about health and improve health outcomes. This talk will detail the program's policies and processes to foster responsible stewardship and use of this valuable resource by enabling high-quality scientific research. This talk will highlight the main features of the biospecimen access policy, the biospecimen user code of conduct, review process for

biospecimen requests, ethical considerations for use of biospecimens including processes for reviewing uses that are potential stigmatizing or harmful to groups and communities. The talk will also provide an overview of the program's processes to monitor and adjudicate potential violations of the data user code of conduct. Finally, the speaker will describe governance structures the program is exploring to harmonize access to data, participants and biospecimens, increase transparency about biospecimen/data uses, and integrate feedback from participants and communities on research priorities or needs to enable beneficial use of these scientific resources.

Language as a barrier to informed consent and patient communications in healthcare: An empirical mixed-methods study from KwaZulu-Natal province, South Africa

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Background: The ability of healthcare professionals (HCPs) to communicate effectively with patients is critical to quality of healthcare service delivery. Barriers to communication arising from illiteracy and language could prevent common understanding of medical procedures, thereby putting patients at risk of providing informed consent (IC) without adequate comprehension. This deprives patients of their ethical and legal rights to full information disclosure, increases medical errors, and could engender medical negligence. Informed Consent is an ethical and legal doctrine which underlies respect for patients' autonomy. To be considered valid, IC must comprise five key elements including full disclosure, capacity, comprehension, volition and agreement, in the absence of coercion or deception. In certain jurisdictions like South Africa, requirements for IC have been codified into national laws such as the National Health Act 2002 which stipulates that HCPs *"must, where possible, inform the user in a language the user understands and in a manner which takes into account the user's level of literacy."* This requirement is a key element of understanding under IC rules. However, full information disclosure and comprehension can be challenging in multilingual societies like South Africa, with its 11 official languages, or in the context of providing healthcare services to complex multicultural populations in this age of globalization and international travel. Therefore language barriers can negatively impact on healthcare service delivery by contributing to errors such as misdiagnosis, non-adherence to prescribed medications, incorrect treatment, and may also impact on patients' human rights, confidentiality, and privacy.
Methods: This report was derived from a cross-sectional descriptive study, using quantitative data and content analysis, designed to evaluate the quality of IC obtained by HCPs, practicing at public hospitals in KwaZulu-Natal province, South Africa. The questionnaire used included questions regarding language and communication barriers encountered by medical doctors and professional nurses when obtaining IC during clinical encounters.
Results: Nine-hundred and twenty-seven participants completed this study, comprising 168 medical doctors, 355 professional nurses, and 404 patients. Most patients in this cohort spoke IsiZulu language (55%), were unemployed (66%), with secondary education (69%). Majority of doctors did not speak the patients' local languages, and required assistance from ad-hoc interpreters including nurses. Therefore nurses were required to work outside their job description by carrying interpreting duties as a form of "cultural brokerage". Most doctors and nurses identified language, poor education, workload, and lack of interpreters, as major barriers to IC in this setting.
Conclusions: Results from this study are consistent with those from other multicultural countries, which identified language as a major challenge to obtaining valid informed consent during clinical practice. Language barriers in multilingual settings can be deleterious to patient

communication and safety. Leading to such problems as failure to obtain valid consent, misdiagnosis, medical errors, and allegations of negligence against healthcare professionals. Provision of trained interpreters may assist with improving patient communications, enhancing the doctor-patient relationship, and improving the overall quality of healthcare service delivery in complex multicultural societies.

The role of clinical ethic committees in Italy on end-of-life matters and beyond

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The regionalisation of Italy's healthcare system resulted in the unintended consequence of a dramatic disparity between the few regions that have set up their network of committees, as required by the law, and the majority that did not. Every region should set up three kinds of ethic committees, operating at different territorial levels: committees focused on, respectively, medical research and clinical practices operate locally, overseen by regional committees. While research committees wield a veto power, clinical ones are only consultive bodies. In theory, every local care authority (or "azienda sanitaria locale", each of them grossly the size of a province) should set up its clinical committee, but in practice many are still missing, while in some cases their appointment drags on indefinitely. Often criticised for their bureaucratic, or legally-oriented approach, instead of an ethic one, clinical committees have been battered by the pandemic: meetings have been postponed, or cancelled altogether during the emergency phase. All this points to a growing feeling of uselessness (a proposed bill even suggested to scrap the term "ethic" from their name): however, increasing pressure exerted on them by end-of-life issues in recent years, while exposing the unsustainability of the current system, may also give reasons for hope. In the most recent episode, a patient known as "Mario" (a tetraplegic man from Marche region on the Adriatic coast) asked for undergoing assisted suicide, presently prohibited by the law, by pleading to a ruling issued by the Supreme Court in 2019, which opened at the possibility of allowing assisted suicide under particular conditions. After a local court ruled twice in favour of "Mario", the issue went under scrutiny at the regional ethic committee, which ascertained the presence of the requirements listed in the Court's ruling, but fell short of clearing the way for the assisted suicide because the absence of a national law means no list of lethal drugs officially recognized for the purpose exists. The statement portrays the limbo in which ethic committees in Italy are stuck: instead of being asked for a counsel in the first place, acting as discussion fora guided by the dialogic principle capable to lead to a shared position, to which all parties should stick from that moment on, they are usually ushered in at the very latest, when things are already messy, and only at the request of judges, as if they were mere legal advisors. There are, however, also reasons for hope: Veneto and Toscana, two of the few regions with an extended and integrated network of committees, are now discussing the implementation of the Court's ruling by officially investing clinical committees of the responsibility of giving a consultive advice prior to final legal decisions are taken and made effective. Moreover, as EU funds pour in to implement Italy's share of EU's "Next Generation" plan, and as proposals for a post-pandemic complete overhaul of healthcare in Italy unanimously show a renovated focus on territorial care, clinical ethic committees, in accordance with their regional counterparts, could and should regain their role as discussion fora for shared decisions on resource allocation in the light of the justice principle, a characteristic provided for by the law but so far disregarded.

‘Diversity competency’ in Polish hospitals internal regulations. Are the EU and Polish guidelines on equal access to healthcare implemented into the hospitals’ policies?

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Poland's socioeconomic composition has been shifting in recent years. To deal with the changes brought by increased social awareness about minority and vulnerable groups and better understanding of the particular needs of these groups, the concept of ‘cultural competence’ has been widely proposed in public health. Because disparities in access to healthcare for minority groups, such as migrants, ethnic and religious minorities and LGBTQ+ persons had been observed, improvement and promotion of the access to healthcare as the fundamental right has been legally enshrined in international treaties (i.e. EU Treaties or the European Charter of Fundamental Rights). Although the term ‘cultural competence’ has been in use for over twenty years, its definition is still contested, with the most appropriate term being 'diversity competence' - implying the broadest population of minority groups, not only limited to ethnic and racial minorities. As such, 'diversity competence' allows the provision of tailored healthcare adapted to the needs of individual patients. This can result in better treatment compliance and health outcomes, and higher patients satisfaction and perceived quality of healthcare service overall.

In this presentation I will focus on how the principles of 'diversity competence' are introduced by Polish healthcare providers, namely policies and procedures, and to a lesser extent in practices, with the question being: how has the issue of social diversity been addressed in Polish hospitals’ internal regulations. I will be referring to the earlier stages and research results of the project “Healthcare as a Public Space” to show how, which and if, and to what extent relevant European Union’s and Poland’s norms and guidelines have been implemented.

In order to answer the research questions, the documentary research was conducted, combined with thematic analysis of materials provided by healthcare institutions (hospitals). Between June and November 2020 contacted were 133 hospitals with the request for relevant internal documents, 14 of them responded; 74 documents were initially analyzed, and 64 were subject to full text analysis. The findings show that most of the supplied Polish hospitals' documents contain only general statements prohibiting discrimination, such as codes of professional ethics, but not specifically addressing the specific needs of ethnic, religious, LGBTQ+ minorities. In received documents the attention is paid to and solutions are proposed to the issues of pastoral care and language barrier, with no arrangements for other minority or vulnerable groups included in the scope of the research. It shows diverse levels of implementation of the EU and Poland regulations on promoting equal access to healthcare. The presentation will be concluded with the preliminary results of the qualitative study (interviews) conducted with the persons identifying as having a minority status in Poland as well as with healthcare workers.

The price of the diversity of bioethics

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Bioethics is an interdisciplinary research area that has grown in recent decades in different environments worldwide. Today, there is no universally shared understanding of what exactly counts as ‘bioethics’ (and as a ‘bioethicist’) nor of what the ‘proper’ methodology of bioethics is. Because of bioethics’ interdisciplinary status, and of associated proximity to several disciplines, academic bioethicists may appear to enjoy a broader set of employment and funding possibilities than do researchers working under the umbrella of one discipline. Moreover, as

major funders (such as the European Research Council) explicitly encourage interdisciplinarity, bioethicists may seem to be well placed to benefit. However, they may also suffer from a lack of shared criteria of what counts as academic merit and how the various types of merits are to be evaluated across disciplines. As each discipline has its own frame of reference for what is important to study and in what way, researching at the intersection of (or migrating between) disciplines may not be seen as excelling in relation to any one's standards. Caught in between disciplines and expectations, there is nothing that a bioethicist can do to improve their respectability, or employability, simultaneously in all the academic worlds to which they may aspire to be affiliated. The same output that can be an impressive achievement in one such world (for example, in philosophy), may not even count as one in another (for example, in medicine): and vice versa.
Insofar as interdisciplinary status is a kind of academic marginality in relation to established disciplines, it is not the only one. Gender, ethnicity, native language, and others, may also have an effect in the different environments with which bioethicists may come into contact. When they intersect, these marginalities can further negatively influence the way in which the value of bioethicists' work is perceived. In this talk, I review the costs to bioethicists that are incurred from the diversity of bioethics, and I explore some possible strategies for improvement of the status quo.

Conscientious objection in the profession of pharmacist. A survey of pharmacists' opinions on the conscience clause in Poland

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In Poland, the discussion on the introduction of the conscience clause in medical law, including pharmacists, appeared due to the resolution of the Council of Europe 1763 of October 7, 2010. Pursuant to the resolution, it was possible to withdraw from performing a specific medical activity due to ethical objections raised by doctors, nurses and midwives. However, this law still does not apply to pharmacists, therefore in Poland there are discussions about granting pharmacists the right to refuse dispensing a drug due to conscientious objection.
The authors of the article decided to clarify the issue of the possible implementation of the conscience clause into the provisions of pharmaceutical law, referring to the example of contraception and presenting the results of the research conducted on the opinion of pharmacists about the conscience clause.
Objective: The authors of the study decided to examine the opinion of pharmacists (from the Greater Poland Voivodeship in Poland) on the conscience clause.
Method: The research was carried out on the basis of a self-developed questionnaire in the Greater Poland Regional Pharmaceutical Chamber. The survey questionnaire was addressed to 105 pharmacists. The participants were asked 29 questions, 21 related to pharmacists' opinions on the conscience clause, and the remaining 8 related to demographic data.
Results: Ultimately, responses were obtained from 100 pharmacists (74 women and 26 men, mean age 34 years). Most of the 82 participants (82%) replied that they had never been subject to a service that was against their conscience. Nevertheless, 18 respondents (18%) expressed a different opinion. Most of the respondents - 59 people (59%) stated that the current law does not precisely define a set of rules established by medical workers using the conscience clause, 8 people denied the decision of the majority of respondents, and 33 people did not have an opinion on this subject. According to 59 people, immediate legal regulation requires establishing the conditions - 50 answers (84.75%), actions guaranteeing the patient access to

receive a specific benefit - 46 answers (77.97%) and determining which group of medical workers has the right to invoke the conscience clause - 42 responses (71.19%).
Conclusions: Most pharmacists are against the conscience clause. Nevertheless, about one-fifth of the respondents were in the situation of performing the service against their own ethical objections, therefore this topic cannot be left without appropriate legal and ethical provisions.

Medical confidentiality, communicable diseases, and public health: the case of HIV positive sex workers

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In this study we analyse the ethical argumentation on confidentiality breaches in sexually transmitted diseases.
The starting point of the study has been the incident of arrest, forced medical examination and public disclosure of HIV positive sex workers by the Greek authorities in 2012. Based on a State legislation for the control of communicable diseases at the time of the incident and under the responsible Public Prosecutor's provision, 17 sex workers were arrested, with their photographs, personal information and HIV positive status disclosed and brought to trial for violation of the sex work legislation, as well as for intentionally causing harm.
The main argument to support this confidentiality breach, was the protection of public health, especially by alerting an unknown number of individuals who had sexual contact with the sex workers, in order for them to be able to seek proper management. Furthermore, AIDS/HIV was considered a major public health threat and its prevention a reason to bend medical privacy, thus the patients were treated as perpetrators and vectors, rather than victims of the disease.
The arguments that opposed that practice were focused on the fundamental concepts of autonomy and dignity in the patient-doctor relationship that cannot be secured in the absence of medical privacy, leaving the patient powerless, as well as on the further stigmatization of the already marginalized sex workers, being used as a scapegoat.
To our opinion, medical confidentiality is not absolute or unconditional and may be restricted in terms of public interest. However, before applying such a restriction, a) we should take into serious consideration the disease severity, the transmission mode, the pathogen infectiousness etc., b) we should abide by the criteria of the proportionality principle and also c) we should try to define how is public interest served best. The conclusion is that the pillory of HIV positive individuals is neither suitable nor necessary to serve the aims of public health, it does not safeguard the trust towards the healthcare system, nor encourages citizens to resort to it whenever they are in need.

Epistemic in/justice in patient participation

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In health care settings, patient participation is increasingly adopted as a possible remedy to patients' suffering from 'epistemic injustice' – i.e., from their unfair harming as knowers. This kind of harm may involve testimonial and hermeneutic injustice, both of which originate in identity prejudices about patients. Testimonial injustice means the deprivation of patients' credibility due to identity prejudices, and hermeneutic injustice means the impoverishment of available interpretative resources necessary for patients to understand their own experiences due to structural identity prejudices. Patient participatory practices, then, aim to enable patients

to understand and express their illness experiences and to institutionalize the integration of their experiences in deliberative settings that predominantly privilege the knowledge of clinicians, policy makers, and researchers. This paper explores this aspired emancipatory value of patient participation. It does so by interpreting patient participation discourses within the 2013-2018 Dutch Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) Health Council advisory process.

ME/CFS is a highly contested condition. Its symptomatic appearance and cause, the evidence base for treatments, and even its existence are subject to fierce controversy for decades now. Consequently, people who are experiencing symptoms of (or related to) ME/CFS report running into disbelieve, stigmas, negative stereotyping, and medical and financial disadvantage. In order to deal with these patients' marginalization, health politicians and policymakers increasingly opt for patient participation in setting policy agendas for research and care. The Dutch ME/CFS Health Council advisory process is a critical exemplar in this trend towards more ME/CFS patient participation. While the Dutch Health Council usually bases their advices on scientific, evidence-based research, this Council's committee was the first with extensive patient engagement; both in the committee itself and through its solicited advices.

This paper shows that in the analyzed case, participating patients (representatives) predominantly offer biomedical knowledge about ME/CFS, and not – as one would expect based on the literature on patient participation – experiential knowledge about their condition. Participating patients frame ME/CFS as primarily somatic, and accordingly, perceive appropriate diagnostic criteria, research avenues and treatment options as quantifiable, objectifiable and explicitly non-psychogenic. This paper argues that such a dominant biomedical patient participatory practice is ambiguous in terms of its ability to correct epistemic injustices towards patients. Biomedicalized patient participation may enhance patients' credibility and their ability to make sense of their illness, but it may also seriously undermine their valid position within participatory practices as well as lead to (sustaining) biased and reductive ideas about who ME/CFS patients are and what kind of knowledge they hold.

Based on these results, the final section of this paper offers an ethical reflection on how to navigate biomedicalized patient participatory practices in order to attain more emancipatory ones. In doing so, it raises the issue whether certain aspects of epistemic injustice, namely the deliberate *muting* or *exclusion* of biomedicalized patient (representative) voices and the *privileging* of other lived, experiential patient voices, may be justifiably incorporated in patient participatory settings.

Operationalizing authenticity – matching treatments with patients or fitting patients to treatments?

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In their seminal work on informed consent and autonomy, Ruth Faden and Tom Beauchamp (1986, 262-269) rejected authenticity as a necessary condition for patient autonomy. Two of the reasons they offered, are the following. First, it is hard to delineate which values, attitudes, etc. are part of the self. Second, it is difficult to know how these elements of the self relate to a particular choice or action. By contrast, Jonathan Pugh (2020, 49-57; and others e.g. White 2018) recently defended the inclusion of an authenticity condition in his theory of autonomy. Pugh answers Faden and Beauchamp's concerns on a theoretical as well as a practical level. On a theoretical level, he defends a coherence theory of the self. On a practical level, he suggests to use Banner and Szmukler's (2013) ideas on "radical interpretation" to asses the authenticity of choices and actions. In this talk, I will not evaluate Pugh's proposal, but focus on an

alternative way, formulated in the scientific literature, to test whether the authenticity condition has been fulfilled.

The scientific literature on decision quality developed independently of the ethical literature on patient autonomy. Decision quality has two components: the knowledgeability of patients and the fit between patients' values and choices. The latter has the same aim as authenticity conditions in theories of autonomy. As much as Pugh's authenticity condition was operationalized by the process of "radical interpretation", the second component of decision quality is operationalized by value-congruence measurements. This begs the question whether value-congruence measurements can live up to their aim and answer Faden and Beauchamp's concerns towards tests of authenticity conditions.

To answer this question, I will present a case study of a value-congruence measurement used in breast cancer care (Sepucha et al.2012) that was recently used as a primary outcome measure in a major Randomized Clinical Trial (RCT) on the efficacy of a Patient Decision Aid (PDA) (Durand et al. 2021). First of all, Sepucha et al. proceed in the absence of a *theory* of the self, and make several *practical* choices that are incompatible with Pugh's theory of autonomy. On the one hand, who is involved in the development of the questionnaire is incompatible with the relational aspects of autonomy. Moreover, which values are withheld and how they are linked with the choice at hand, is guided by a regression model that violates the is-ought gap. By consequence, these value-congruence measurements cannot answer Faden and Beauchamps concerns.

In short, these value-congruence measurements systematically distort the values patients hold and cannot determine whether patients' values correctly relate to their choices, thereby implicitly denying the diversity of values patients hold and the personal trade-offs they make between them. The upshot of this talk is that by confronting the ethical literature on authenticity and the scientific literature on decision quality, we try to check for the ethical acceptability of what is technically possible, without overlooking technical possibilities to realize the ethically desirable.

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Intersectionality and autonomy in bioethics: in search for diversity and convergence

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The bioethical field, as a product of Western biomedicine, is struggling with the complexity of diversity and power differences. Yolonda Wilson, Amina White, Akilah Jefferson and Marion Danis (2019) target article 'Intersectionality in Clinical Medicine: The Need for a Conceptual Framework' and its accompanying commentaries published in *The American Journal of Bioethics*, shine new light on this debate through a dialogue on the benefits of adopting an intersectional approach in bioethics. In this paper I want to further consider the opportunities for applying intersectionality as critical social theory to the theoretical debate on respect for autonomy in bioethics. The first section of this paper provides an overview of 'Intersectionality in Clinical Medicine' and its commentaries. These suggest that there are still analytical spaces around intersectionality that can and should be expanded. In the second section, I argue that a dialogical engagement between bioethics and intersectionality could be more widely used as a pathway to normative theorizing about autonomy. I suggest that relational approaches to autonomy are useful to create some convergences and focuses on two overlapping premises: relationality and justice. The heuristic of intersectionality can draw attention to power dynamics that are constitutive for stratification mechanisms that are generally overlooked or silenced when bioethicist argue about ethical dilemmas of autonomy. Finally, I refer to the case of egg freezing as an illustration of the analytical value that intersectionality can offer in a bioethical debate that has tended to focus on the scope of reproductive autonomy on behalf of a very generalized category of women. I ask a different set of questions about the complex relationships between race, class, age, sexuality and gender that are not addressed by the early literature about this topic. By foregrounding an intersectional approach to this debate, the complicated relational and justice concerns of reproduction are better brought into focus.

Conscientious objection in healthcare, moral complicity, and the duty to refer: Taking reasonable pluralism seriously

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Conscientious objection (CO) has been high on the agenda of medical-ethical debates in recent years. Following Marc Wicclair, it has become common to distinguish between conscience absolutism (the position that health professionals should be more or less free to refuse to perform any activity that they consider immoral), the incompatibility thesis (the thesis that the practice of conscientious objection is incompatible with medical professionalism), and a compromise view which tries to strike a reasonable balance between the interests of health professionals in maintaining their moral integrity and the interests of patients in having timely access to all lawful medical treatments.
Among those who argue for a limited right to CO, one particularly disputed issue concerns the extent to which professionals who refuse to provide a certain treatment themselves for reasons of conscience should be required actively to support the patient in his/her search for alternatives (by informing him/her about the relevant options, referring him/her to a colleague, facilitating transfer to another institution etc.). In espousing what he calls the "conventional compromise", Dan Brock calls for the objecting professional both to inform the patient about the service if it is medically relevant to his/her condition and to refer him to another professional willing and able to provide the service. Wicclair is somewhat more cautious but argues in a similar direction. Crucially, both grant the conscience absolutist's claim that disclosure and referral

might render the professional morally complicit in the practice to which he/she objects. Their argument for a duty to disclose and refer does not rest on the assumption that disclosure and referral are morally innocent, but on the claim that, if it comes to disclosure and referral, a professional's legitimate interest in maintaining his/her moral integrity is *overridden* by his/her obligations to the patient.
My presentation tries to show that a more positive case can be made for a duty to refer (and, more generally, to actively cooperative in fulfilling the patient's request, even if one refuses to provide the treatment oneself). The basic idea is that the various conceptions of moral complicity that Brock, Wicclair and others discuss are ill-suited for dealing with moral disagreement under the conditions of reasonable pluralism because they presuppose that a certain practice is *unambiguously* wrong. Accepting what Rawls calls the burdens of judgment, however, calls for a more qualified moral judgment of contested practices such as abortion or assisted suicide on the part of their critics, and, consequently, for a less demanding conception of moral co-responsibility. Objecting professionals can be asked to inform and counsel patients about the service they reject, refer them to a non-objecting professional etc., not only because (and insofar) as this is necessary to secure patient access, but in order to show patients that they respect their views, thus reciprocating the respect that is shown to them by the majority in the first place.

The empty place of knowledge. Why ethicists should be aware of becoming experts.
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From the very beginning of the pandemic, ethicists and philosophers were engaged in committees writing guidelines or giving advice to governments regarding Covid policies. While usually philosophy is somewhat considered to be the most useless discipline on earth, all of a sudden, a lot of us were in charge at the centre of power. I was for instance asked myself as expert in Belgium, writing guidelines who could potentially decide upon people's live: priorities in care, priorities in vaccination or other decisions to be made. Ethicists and philosophers became experts in the frontline of care and of politics.
Of course, this has helped in more than once way governments or epidemiologists as support for frameworks to be rolled out. Nevertheless, there are some pitfalls in this matter. I mention only some questions related to these pitfalls:

- If ethics becomes a matter of expert decisions only, what about the democratic character of it?
- If ethicists become experts, are they running the risk of becoming toothless fees and lose their sense of critics towards the ones in power?
- Is knowledge not always also something of not knowing and are philosophers not the ones to remind us of that?

With Claude Leforts theory of the empty place of power in mind, I will analyse the dilemmas and challenges regarding the place of ethics and professional ethicists in modern democracy. More general, Lefort can help us analyzing that during the crisis, if a lot of people asked for commanders in chief ready to take the right decision, exactly this demand has put the democratic character of many decisions under pressure. It is important to learn from this pandemic also from this perspective.

Meaning of being. About closeness in the treatment process from a law and psychology perspective

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In fact, doctors of various professions participate in the life of a person at all stages of his life - from birth to death. As a rule, a doctor and a patient have a specific "bond" based on trust and care. Sometimes, treatment and illness influence and involve other people and their close relatives. What relationship is formed between the doctor and patient's relatives? How the value of their presence should be treated in this context – as something positive or as obstacle for patient and doctor? How potential of real bonds can affect treatment process and how it can be used by doctors? There is also question about autonomy of a patient - what should relatives know about our health and do they have any title to that? Do we „belong" to our relatives in some extent? How physicianshould treat close relatives and recognize them? It is also important to indicate how doctors determine „close relations" and how they should identify them.
In the speech based on the analysis of legal solutions, judicature and philosophical foundations, the impact of "close relatives" on the treatment process will be considered – who is "close relative" to the patient, what is the information scope for "close", the participation of close relatives in treatment and on the other hand - the issue of medical confidentiality and it's limits, the scope of information that the doctor has about the patient and his close persons, the doctor's attitude towards the patient and close relatives.
I want to analyse this complex relation (patient-doctor-close persons) from the perspective of human relationships filled with different emotions, feelings, gestures. I will try to show that, in fact, the treatment process often creates a complex emotional relationship filled with the emotions of the doctor, patient and loved ones. The question therefore arises about how to use the potential of these emotions, whether they are a desirable or unavoidable product of interpersonal relationships

Accounting for the Referral Requirement: Conscientious Objection and the Idea of a Morally Permissible Moral Mistake.

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Despite the high degree of effort that has been expended, the matter of conscientious objection (and conscientious refusal) in medicine and healthcare continues to trouble the field of bioethics. Furthermore, whilst the fundamental issue concerns our response to moral difference and good faith disagreement, the debate seems to be subject to an increasing degree of polarization. On the one hand there are those who would reject any and all claims. As they have it, patients have a legitimate right to access established medical treatments and procedures. To impede them from doing so is morally illegitimate. Such a position clearly rejects the kind of compromise required if we are to effectively accommodate a plurality of moral perspectives.
On the other hand, there are those who see preserving the right to conscientiously object as morally imperative. Some authors who fall into this camp have recently argued that the referral requirement—the obligation placed upon conscientiously objecting healthcare professionals to effectively refer patients to another provider who holds no such objection—is itself an morally intolerable imposition (cf. Oderberg 2018). As they have it, acting in this way renders those who conscientious object complicit in the very act they find morally objectionable. The implication of such a position is that the kind of compromise required to effectively accommodate a plurality of perspectives is morally invalid.

As Ben-Moshe recently put it, if one wishes "to allow for conscientious objection … and avoid the complicity that is associated with requiring objecting practitioners to refer patients to non-objecting practitioners, [one] will have to come up with a creative solution" (2019; 409). Drawing on the notion of morally permissible moral mistakes (Harman 2016) this paper will present one such creative solution. Indeed, as I will present it, the idea of morally permissible moral mistakes not only helps us understand the referral requirement it can also shed light on conscientious objection itself.

In the first instance I will argue that, when seen from the perspective of those with conscientious objections, the act of referring patients to another non-objecting provider can be understood as a morally permissible moral mistake. As such, the degree to which they are implicated in the objectionable service is comparable to the moral complicity entailed by continuing to work within a healthcare system that provides such services.

In the second instance, I will argue that, when seen from the perspective of those who do not conscientiously object, refusing to be involved in an established medical treatment can be understood as a morally permissible moral mistake. As such, it is morally permissible for conscientious objectors to make the moral mistake of impeding a patient's access to a particular medical service, as long as the patients' inconvenience is minimized to the greatest possible degree.

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Intersectionality as a critical tool to account for diversity within mental health care – a systematic concept analysis

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Discrimination of people with severe mental illness based on their diverse social identities is a pressing problem in mental health care and constitutes a barrier to justice. Service users' social identities are marked by multiple categories of diversity such as mental and psychical ability, gender, sexual orientation, and race. Only last year, the German Society for Psychiatry, Psychotherapy, Psychosomatics and Neurology has called for research on discrimination and discrimination-free access to mental health care. As such, providing the conceptual basis for a non-discriminatory mental health care, apt to account for diversity within the clinical practice, should be a primary concern of mental health ethics.

To analyze discrimination under acknowledgment of people's diversity, the concept of intersectionality has emerged as an analytic tool. Originally developed by Black Feminist activists, the concept has since received much uptake within academia, including the field of mental health research. Intersectionality rejects single-axis analyses which focus on singular categories of diversity (e. g. being a woman) but stresses to take into account within-group differences (e. g. being a *white* able woman, being a Black poor woman). It has different ontological and epistemic core characteristics, such as the co-constitution and interdependency of social categories, or the complexity and context-dependency of experiences of discrimination.

Due to its conceptual complexities, the application of intersectionality within mental health care research is faced with numerous challenges. First, intersectionality has initially been developed as a practical tool for activists to make specific experiences of discrimination intelligible, and not as a scientific method. Therefore, many authors describe difficulties in operationalizing intersectionality for quantitative and qualitative research. Second, many approaches have been criticized for using the label of intersectionality without paying attention to the different epistemic and ontological characteristics of intersectionality. Thus, they fall short in applying intersectionality correctly and using the concepts critical potential.
Therefore, there are important differences in the use of intersectionality. We can understand the concept as originally construed by Black feminist activists and philosophers as the "target concept". In opposition, the "manifest concept" within psychiatric research is the concept that has evolved through the application of different intersectional approaches within psychiatric research on discrimination. Implicit differences between the target concept and the manifest concept may lead to biased interpretations of research results. It may thus constitute a barrier to meaningful research on discrimination and diversity.
In this paper, we present our results from a systematic literature review on the use of intersectionality in research on discrimination within mental health care. Based on a systematic concept analysis in the relevant empirical research, we compare the manifest concept(s) to the target concept, focusing on the relevant epistemic and ontological characteristics of the target concept. Finally, we present a conceptual framework of intersectionality that is apt to account for the specific aspects within mental health research while respecting core characteristics of the target concept.

Ethical Foundations for Biomedicine in Diverse Societies
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Cultural diversity presents numerous challenges for biomedical research. I will describe an ethical framework [cf. (Fedyk, 2017, Chapter 7)] that allows researchers to harmonize the reality of cultural diversity with continued progress in biomedical research. The specific problem that my presentation will address, thus, is the tension between the scientific objectivity of biomedical research and the moral relativity and pluralism of that are often by-products of cultural diversity.
My proposed solution consists of "injecting" into biomedical research an ethical framework that converts the tension between objectivity and pluralism into an opportunity to produce ethical insights as ordinary by-products of biomedical inquiry.
The idea most central to the ethical framework is that the ethical norms which structure biomedical research can, and should, change. Accordingly, the function of the ethical framework is to define a process according to which these changes can be both *rational* — meaning, guided by rigorous scientific evidence and scholarly considerations — as well as *socially responsive* — meaning, sensitive to the structure and values of the populations of people impacted by biomedical research. This would make the ethical norms which structure biomedical research outcomes of processes that are partly analogous to bicameral legislation — that is, the content of the ethical norms would be jointly determined by both facts about different social realities and the content of contemporaneous scientific research.
I contend that three norms are sufficient to "unlock" such a bicameral process. The first is a novel definition of an ethical norm: *a norm is ethical if it has priority over all other norms that are operative in a particular context*. The second is a methodological norm that I claim should cover all biomedical research: *a norm should be categorized as an ethical norm if either it has*

been shown (because of its prior adoption) or it can be shown (by sufficiently rigorous scientific evidence) to produce outcomes that are better than the status quo for the people who are impacted by the adoption of the norm. The third norm is the principle that *all populations of people should be served by biomedical research communities whose research is governed by the first two norms*.

I will conclude with a brief discussion of case studies from nursing science which shows that "bicameral" practices which look like implementations of my three norms already exist. The case studies are worth considering for two reasons. First, the concrete illustrations they provide count as an argument for the viability of my proposal. Second, these examples address the concern that my proposal is too deeply counter-intuitive to be worth pursuing.

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Public engagement on Germline Genome Editing: decreasing or replicating wider polarisation in society?

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During the 2010's, the CRISPR-Cas9 technique – with its promise as a new, more efficient, more accurate and feasible form of gene editing – has reignited a popular awareness of genetic science to a degree not seen since the advent of the Human Genome Project of the 1990s. It is now one decade since the 2012 paper that Doudna and Charpentier co-authored and there have been a number of promising developments of the CRISPR tools in research. Throughout this time, there have also been developments that have caused concern and outrage, particularly with the infamous 2018 announcement of the first gene-edited babies. Concerns have been raised about risk and safety, impact on future generations, problematic non-medical uses, potential impacts on women and persons with disabilities, and wider impacts on broader society in the form of increasing inequalities (gender, racial, ability) and other concerns of social justice, patenting and ownership issues, and concerns over eugenics. In response, a number of statements (Lanphier et al 2015; Chan et al 2015; Andorno et al 2020), Reports (Nuffield 2016, 2018; NASEM 2017; National Academies/Royal Society 2020; WHO 2021), International Summits (2015, 2018, 2022), and a voluminous academic literature have emerged. Throughout such statements, reports, summits and in the literature, there have been numerous, urgent calls for public engagement and the desire for various degrees of social consensus before the technology either proceeds at all, or before it continues to proceed in various directions (Baltimore et al. 2015). Such calls range from improving science communication (top down) to more deliberative forms of public empowerment (Baylis 2019). It is held that governance of germline genome editing should be informed by robust public engagement & with a reasonable degree of social consensus regarding wider societal impact. Key rationale is for quality (a wider diversity of perspectives) & legitimacy (allowing people a say in things affecting their lives) of the resulting governance. This process will take place within a broader socio-political context of increasing polarisation, misinformation & questions over the degree of (dis)trust of science & medicine. This requires a review of the existing public engagement suggestions from the GGE literature (including reports & other statements), as well incorporating insights from forms of engagement in the wider field of genetics & research into public trust. There are a number of directions that public engagement on germline genome edit can take – from mere science communication to substantial forms of public empowerment. GGE public engagement proposals vary in terms of their degree of genuine deliberative engagement, suggesting that some may be more effective than others, in terms of their ability to reduce polarisation of

viewpoints, correct misinformation & increase meaningful trust. Genuine participatory-deliberative engagement – characterised by mutual respect, co-operation & genuine openness to alternative & opposing views – will be needed to counter the levels of distrust & polarisation seen in the context of genetics & wider society

The Suffering of the Many Outweighs the Suffering of the Few or the One.

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Utilitarianism, as a moral theory, has been criticised because its application often results in unpalatable conclusions. Accordingly, utilitarians have sought to adjust the theories in a way which resolves the usual accusations of unsuitability. These results are often unsuccessful and may even generate further problems.

Matti Häyry offers a treatment of utilitarianism which he calls 'liberal utilitarianism' and advances a 'greatest need-satisfaction' principle. According to his revision "it is always right to maximise the satisfaction of needs, provided that the satisfaction if the more basic needs for survival, health, well-being, and happens is not prevented by the satisfaction of less basic needs…"[1] In addition, his interpretation shifts the focus away from the positive principle of 'maximising the greatest good to the greatest number', to the negative principle of 'minimisation of harms to the greatest number'. Häyry's iteration is not without concern, nevertheless, it also appears to offer enough significant improvements to classical utilitarianism to be worthy of further investigation.

With the recent cancellation of Singer's book promotion in New Zealand due to his position on euthanising newly-born disabled children, the classic utilitarian position on disability has once again been brought under scrutiny. While utilitarian concepts often fit well with the distributive justice requirements of welfare states, the conclusions that obtain are often unacceptable and inadequate; the QALY, for instance, is toted as an effective utilitarian calculus of cost-effectiveness — however, it has also received criticism for being neither a proper formed utilitarian calculus nor one which responds appropriately to the concerns health care users.

The negative principle buried in Häyry's revision bodes well, however, as this iterative process may well permit a steady increase in the well-being of disabled persons through a more perspicacious use of state services (perhaps even indicating the development of new services, such as a sex doula program). With this in mind, this paper seeks to determine whether or not liberal utilitarianism can stand as useful tool in matters of disability, distributive justice, and health care; and whether or not there are any unwelcome side effects of this revisionary moral theory.

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Precision health/ ethical ambiguity. How much cancer can we afford to prevent?

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"Precision medicine" and "precision health" seem to complement one another. When faced with a life-threatening metastatic cancer we want an effective targeted cancer therapy. We would also rationally prefer whatever medicine might offer to prevent the emergence of a life-threatening cancer, the goal of precision health. In a recent book, *The First Cell (and the human*

costs of pursuing cancer to the last), Azra Raza, an oncologist for 30 years, argues that we are wasting tens of billions of dollars annually on extraordinarily expensive cancer therapies that yield only marginal gains in life expectancy and maximal increases in suffering. She believes *these resources* (not resources from heart disease or anything else) should be redirected to destroying cancer in its earliest stages, those "first cells," through multiple preventive strategies. One such strategy involves a new liquid biopsy (GRAIL) that can detect 20 different cancers in very early stages by examining cell-free DNA. Cost might be $500. But 170 million anxious US adults (and likely 350 million EU adults) would be candidates for this test annually at an aggregate cost of $85 billion in the US or €160 billion. From the perspective of health care justice, who should pay for these tests? Who should be denied access to these tests at social expense? Would justice or efficiency require foregoing $85 billion (€160 billion) in metastatic cancer care to pay for this preventive effort? Another strategy would involve doing whole genome sequencing of everyone, starting at birth, to establish a polygenic cancer risk score. What then? How would we imagine using that information for cancer prevention? At what cost?

Here are our key questions: What would a "just enough" balancing of preventive and therapeutic objectives look like? I critically assess several policy options for addressing these questions, including the statistical lives versus identifiable lives problem. I argue, for example, that the GRAIL strategy, applied *en masse*, is both unaffordable, irrational and unjust. The same will be true for the whole genome sequencing strategy. A just and affordable cancer prevention strategy must ultimately be the product of a fair and inclusive process of rational democratic deliberation that incorporates a pluralistic understanding of health care justice as well as relevant medical and scientific information. "Pure" utilitarian, egalitarian, prioritarian, libertarian or sufficientarian conceptions of health care justice will not yield ethically defensible trade-offs regarding preventive and therapeutic efforts to address cancer care that is affordable. Nor will they yield fair prioritization with regard to either preventive or therapeutic efforts in cancer care.

Objectives: Identify justice-relevant considerations for assessing several different cancer-prevention strategies.

Identify "just enough" trade-offs between cost of cancer prevention and cost of metastatic cancer treatment.

Analyze from an ethical perspective the statistical lives versus identifiable lives problem in the context of cancer care and prevention.

A "Figleaf" Phenomenon and How to Deal with it

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A metaphor of ethics as "fig leaves" that hide economic interests of biotech and pharmaceutical companies leads us towards a broader question about the misuse of ethics as a discipline in different fields of public life. It should be noted that pharma industry is not a unique field where ethics is used as a shield to cover very different motives and interests. For example, even a stronger wording of a "figleaf for structural violence" was used already in 2005 by R. E. Ashcroft describing a rubberstamping function of ethics committees in the transition countries approving research projects without a proper review, just to please foreign partners or research sponsors. Institutionalization of research ethics could serve as a good example to analyse why ethics is paradoxically used to hide some "unethical" interests and what lessons can be learned by bioethics consultants in other fields, such as pharmaceutical industry, to prevent the phenomenon of ethics misuse.

Informed consent: is it still a fundamental principle of human research?

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Specific informed consent has been one of the most fundamental principles of human research since the adoption of the Nuremberg Code in 1947. However, developments of human subject research in the beginning of the 21st century aiming at personalized medicine and based on the use of "big data" as well as sharing of personal health related data/biological materials collected in different research projects, have challenged the paradigm of research ethics centered around the principle of informed consent. There have been two important structural changes gradually introduced into the international ethical guidelines, legal instruments and "soft" law tools dealing with human research. First, a distinction between consent to bodily intervention and consent to personal health data processing was made explicit in recently adopted documents. For example, such a distinction can be seen in the Declaration of Helsinki (starting from its 2008 edition), the 2016 CIOMS Guidelines as well as legal tools for biomedical research of the Council of Europe and the European Union. This distinction between informed consent in research projects involving humans and consent under data protection law becomes even more explicit with coming into force of the new EU *General Data Protection Regulation* (*GDPR*).
Secondly, and what is particularly relevant for this discussion, regulations and guidelines on human research have introduced modifications and exemptions from the informed consent rule in order to facilitate sharing of research data for future unspecified research and/or sharing of data that was already collected for other purposes. Modifications of informed consent rule most often follow the scenarios of "broad" consent, "dynamic" consent, or "informed opt-out" as defined in the CIOMS Guidelines. However, a more radical solution is to waive consent requirement and follow its legal analogy of "compatible use" enforced by the GDPR. The problem is that the "compatible use" regime allows a remarkable exemption from the consent rule as it explicitly notes that all personal health data can be processed "for … scientific or historical research purposes or statistical purposes" without the data subject's consent (Article 6(4); Recital 50). Of course, important safeguards, such as technical and organizational measures to ensure principle of data minimization, have to be followed in this case. However, these safeguards do not provide the same rights as compared to what the consent rule is supposed to cover. Although modifications and waiving of consent are not new and have been applied for decades in research with human biological samples and data, the "compatible use" mode by the GDPR can make waiving of consent a prevalent scenario rather than the exceptional case in human research, which is a particularly important shift in the context of research with "big data".
Therefore, this paper aims at exploring the mentioned exceptions from the consent rule as well as ethical challenges arising in the context of these developments.

Moral Challenges in Transgender Care: A Thematic Analysis Based on a Focused Ethnography

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Background: Treatment teams providing transgender affirming medical care are inherently faced with various kinds of moral and ethical dilemmas and questions, which are becoming

even more pressing due to increasing treatment numbers and public attention for transgender care. Little is known about what kinds of moral and ethical challenges manifest in clinical practice.
Aim: The aim of the present research was to map the moral and ethical challenges of healthcare professionals working in a specialized multidisciplinary transgender care center.
Methods: Over a period of 7 months, during a focused ethnographic study, data were collected through participant observation of multidisciplinary team meetings, observation of individual psycho-diagnostic assessment sessions with clients, and analysis of transcripts and reports of a series of moral case deliberations.
Results: A thematic content analysis of the data identified various implicit and explicit moral and ethical challenges around the following six themes: (1) assessing eligibility; (2) content of treatment; (3) sequential order of the treatment steps; (4) role of the clinical guidelines; (5) differing notions regarding gender identity, and (6) decision-making process.
Conclusions: Our research provides a detailed insight into the way healthcare professionals experience these moral and ethical challenges and how they are related to (local) guidelines, the multidisciplinary character of GD care, and its inherent implicit and explicit gender norms. Our findings suggest that good transgender care may profit from continuous multidisciplinary deliberation of and sensitivity toward the normative dimension of transgender care. The paper ends with recommendations for ethics support mechanisms in transgender care.

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Challenges in (shared) decision-making in gender affirmative medical care: an ethical analysis

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Background: The notion and practice of shared decision-making gives rise to a plethora of moral challenges. In gender affirmative medical care, the absence of a firm (long-term) evidence base, diverging values and diverse conceptualizations of gender dysphoria directly impact such moral challenges as well as the organization of the decision-making process. Against this background, proponents of the dominant care model (i.e., the Standards of Care) often dissent with those in support of an alternative, emerging care model (i.e., the 'Informed Consent model). These 'care models' outline criteria for hormonal and surgical treatments and visions for (shared) decision-making. The literature suggests that in both, decision-making raises many complex clinical ethical challenges to those involved. In the discussion of these care models and ethical challenges, (bio)ethical concepts such as 'client autonomy' are often referred to, but left unsubstantiated. Explicating the normative assumptions regarding decision-making underpinning these two care models can help to better understand the key clinical ethical challenges related to decision-making experienced by stakeholders and inform the debate.
Aim: The aim of this paper was to make explicit the normative assumptions regarding decision-making and client autonomy in two care models for gender affirmative medical care in order to elucidate the key clinical ethical challenges related to shared decision-making.
Methods: A narrative literature review of papers on ethical challenges experienced by stakeholders in gender affirmative medical care and an ethical analysis drawing from ethical theories on client autonomy and (shared) decision-making.

Results: The Standards of Care stipulate that clinicians engage in both assessorial and supportive tasks regarding client autonomy. The assessorial tasks hinge on weak paternalistic assumptions regarding the decision-making competency of clients and presuppose a notion of client autonomy as the ability to critically reflect. The supportive tasks, on the other hand, rest on deliberative assumptions regarding decision-making and imply a more relational notion of client autonomy. Contrarily, the Informed Consent model can be rendered an archetypical informative model underpinned by a negative, liberal legal notion of client autonomy. In this normative ambiguity and inexplicitness clinical ethical challenges related to (shared) decision making abound.
Conclusions: By understanding the clinical ethical challenges experienced by stakeholders involved in light of the implicit normative assumptions regarding decision-making and client autonomy, this paper demonstrates how both care models may actually thwart the desire of clients and clinicians to work collaboratively. This paper ends with suggestions for empirical ethical research to foster sensitivity towards, and jointly handle, clinical ethical challenges related to (shared) decision-making in gender affirmative medical care.

Artificial Intelligence (AI) and Islamic Ethics: The Moral Dilemmas of Humanoid Robots
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(1) Artificial Intelligence and Religion: The emerging field of AI and its various applications are increasingly penetrating almost all aspects of our modern life, from healthcare services to religious practices and rituals, and thus are gradually transforming our world. Almost all moral traditions, and Islam is no exception in this regard, are setting their agenda to examine the moral questions and challenges posed by the AI field and its unstoppable applications (Geraci, Robert 2010).
This presentation will explore one of the understudied topics in this area, namely the interplay of Islamic ethics & AI applications. Islam, as a religio-moral tradition, can be roughly divided into two broad domains. The first domain examines God-human relationship and this has always been the subject of the scholarly discipline of Islamic theology (*kalam*). The second domain assesses the human-human relations, where the discipline of Islamic jurisprudence (*fiqh*) has been playing a key role throughout history. In the two sections below, the focus will be on specific moral dilemmas related to humanoid robots so that the domains of both theological and juristic ethics will be represented.
(2) Humanoid Robots: Theological Ethics: If replicating human intelligence is a common feature among almost all AI applications, humanoid robots in particular resembles humans in shape as well. Throughout the intellectual history of Islam, the human species has always been regarded as a striking marvel of God's unsurpassed power of creation, which proves His Oneness. Making idols that assume the shape of humans to be worshipped next to God was harshly condemned in Islam because this contradicts the theological principle of Divine Oneness (*wahdaniyya*). Additionally, making human-like idols was prohibited because it was seen as mimicking (*mudahaat*) a divine act which is exclusive to God, namely creating humans. This historical background made various Muslims, including engineers interested in the industry of humanoid robots, to wonder whether, and why, the historical reservations against making human-like idols would apply to the modern humanoid robots.
(3) Humanoid Robots: Juristic Ethics: In the human-human relationships, using humanoid robots to replace one's sexual partners (sex robots) or to replace healthcare providers (care robots) poses complex religio-ethical questions for Muslims. Concerning sex robots, Islam categorically prohibits sexual relations outside the institution of marriage, which can only take

place between two humans, viz., man and woman. However, the illicit sexual relationship also becomes a sin only if takes place between two humans. As for care robots, providing well-tailored and efficient healthcare services has usually been seen as one of the collective obligations that Muslim societies should exert all possible efforts to achieve. On the other hand, the very human-human interaction is in Islam a moral act by itself, which is to be commended by humans and rewarded by God, especially when it has to do with taking care of vulnerable groups such as the elderly and sick people.
In order to fill in the current lacuna in academic scholarship on the above-sketched issues, the presentation will examine these moral issues and dilemmas by consulting a wide range of primary and authoritative sources in the Islamic tradition, besides the available few secondary sources.

Healing at a distance: Phenomenological perspective on the quality of the patient-health care provider relationship in teleconsultation

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The global crisis of Covid-19 pandemic has considerably accelerated the use of teleconsultation (consultation between the patient and the health care provider via video platforms). While it has some obvious benefits and drawbacks for both the patient and the health care provider, it is important to consider the possible impact that teleconsultation has on the quality of the patient-health care provider relationship. It has been pointed out by phenomenologists of medicine that a major factor influencing the quality of the patient- health care provider relationship is the focus of the health care provider on the patient as a mere physical body needed to be fixed (Toombs 1992; Svenaeus 2021; Carel 2016), which leads to the objectification of the patient as a disease entity and the accompanying feelings of alienation and the loss of agency on the part of the patient. The aim of this paper is to find out if online clinical encounter, mediated by digital technology (videoconference communication) influences the quality of the patient-health care provider relationship. More specifically, I will focus on the question: does the digital medium in teleconsultation contribute to the objectification of the patient? I will approach this issue from the phenomenological perspective combining both insights from the phenomenological tradition (concepts of the lived body and object body / illness and disease) and the results of my phenomenologically informed qualitative research study of the patient experience of teleconsultation (the patient experience of herself, her experience of the doctor and her experience of the interaction between herself and the doctor), using "Phenomenologically Grounded Qualitative Research" methodology (Køster & Fernandez, 2021). The theoretical background against which I have developed this study is discussions within phenomenology of medicine about the different sources of objectification within clinical encounter (the medical gaze and the medical technology), and the negative impact objectification has on the quality of patient- health care provider relations.
By referring to the phenomenological distinction between the lived body and the object body (and the associated distinction between the illness and the disease), I will argue that despite the theoretical reflections about the alienating nature of technologies, it is the patient's lived body and not the object body, which is at the center of teleconsultation. The patient's focus on her body as an object during teleconsultation is diminished, primarily because of the attitude of the health care provider. Because of the lack of the physical body of the patient online, the health care provider is forced to focus on the story of the patient, which gives her access to patient's lived experience of the illness. This in its turn has a beneficial impact on the patient's embodied possibilities of action and interaction during teleconsultation. Because the patient experiences

herself primarily as a lived body, her sense of agency (her sense of control and responsibility) also increases, which to some extent at least disrupts hierarchical patient-physician relationship.

Access to healthcare of minority groups in Croatia - comparison of legal regulations and practices

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One of the fundamental documents at European Union level is the EU Charter of Fundamental Rights. By its acceptance and subsequent incorporation into primary legislation, the European Union has moved its prime focus to the necessity to protect human rights on its own territory. The accession of the Republic of Croatia to the full European Union membership during the last enlargement in 2013, which brought Croatia to become the 28th EU member, was preceded by the process of harmonization of Croatian national legislation with the *acquis communautaire*.

The right to health care, one of the fundamental human rights, has been guaranteed by the Constitution of the Republic of Croatia. The legal act ensuring Croatian implementation of anti-discrimination practices is the Anti-Discrimination Act, which came into force in 2009.

The Croatian Anti-Discrimination Act recognizes seventeen grounds on which discrimination is prohibited and applies to the treatment of all state entities, bodies of local and regional self-government units, legal entities vested with public authority, and to the conduct of all legal and natural persons in ten areas including the area of health care.

In our presentation, we will compare two levels of indicators of access to health care for minority groups, potentially vulnerable due to on ethnicity, religion, sexual orientation and gender, gender expression and gender identity. More specifically, we will incorporate results of research conducted within the EU research project "Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe".

The first level refers to the available internal documents of Croatian healthcare institutions concerning access to healthcare for mentioned minority groups. Using the method of qualitative thematic analysis, we have examined materials from Croatian hospitals and distinguished common themes and specific statements relating to the issue of access to healthcare.

The next level includes the results of the last phase of our research. In this phase, interviews were conducted with members of minority groups and hospital employees. Through the results, we gained knowledge about real events in the daily practice of health institutions. Or, at least, about the subjective experience of these two groups of participants.

In the final part of the presentation, we will draw conclusions about the similarities and differences between the levels in accordance with national legislation dealing with the right to health care for minority groups in question. Furthermore, we will offer some suggestions for improvements of regulation in the Croatian healthcare system governing access to healthcare for minority groups.

Deliberation and dialogue in hermeneutical clinical ethics: whose horizons should be fused?

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This paper re-examines the theoretical foundations of moral case deliberation (MCD) and inquire for the implication of hermeneutics in clinical ethics. MCD is a semi-structured way to

understand a given case in the clinical setting deeply and to solve its ethical problems. It is an alternative or opposite method originated in Northwestern Europe against the dominant styles of clinical ethics support practices in the United States, where clinical ethics committees and experts such as ethics consultants are fully utilized. MCD is a multidisciplinary practice on the basis of the conversational dynamism among the team on the ward. As the philosophical backgrounds of MCD, Gadamer's hermeneutics and Habermas' discourse ethics are usually referred to. In this paper, we are focusing on the former. Some authors have addressed the significance of trying to broaden and deepen our understanding about a given case from various angles. Through deliberation and dialogue on the ward, each participant is supposed to listen to the other members' understanding or interpretation about the circumstances of the case, to understand each other, and to open up a new perspective by synthesizing their opinions. This is often likened to "the fusion of horizons." Here a horizon means a perspective of each medical professional. Against this idea, in which mutual understanding of the staffs should be among others aimed at, we argue that what are to be fused are the horizon of the given case in itself and the horizons of medical professionals' views. Seeking a more plausible approach to the case itself should be put priority rather than harmonizing various voices of the professionals or promoting the team-based medical practices.

A critical evaluation of the 'right to try' approach to the early access to medicines problem

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It is generally recognised that there are situations where it is rational for patients to seek access to medicines before these medicines have been licensed. If a patient has a progressive, life-threatening condition for which there is no current effective treatment and a new promising treatment is in development, the point at which it becomes rational for an individual patient to seek access may come before it becomes rational for a regulator to license the product and allow it on the market. This aligns with an ethical rationale of compassion towards patients who have no other treatment options (although compassion and 'compassionate use' is perhaps not quite the right description for what goes on).

This has led to the suggestion that countries should implement 'right to try' laws that 1) prohibit a regulator from blocking access prior to licensing, 2) provides qualified immunity to the owner of the drug if it decides to supply it in response to a right to try request, and 3) specifies what, if any information can or should be collected when the product is supplied. Right to try laws thus, in reality provides a set of rights not to be frustrated by the state and its agencies in trying to get access, but not a right to access as such.

This paper argues that the 'right to try' approach to early access is problematic because it is ethically problematic, and because there is a better approach which dominates right to try on all important decision-making parameters.

The main ethical issue raised by right to try legislation is that there are good reasons to believe that access will be extremely inequitably distributed. Only resourceful patients with resourceful and well connected doctors will request and get access. Although right to try is not a formally unjust policy, its implementation will have unjust results.

The other main approach to early access is an early access program (EAP). In an EAP the owner of the drug designs a program with eligibility criteria and rolls this out in a systematic way. The following table compares the main features of right to try and EAPs, and shows that early access programs dominate on every single ethically relevant feature. The presentation will explicate each comparison.

Feature of approach	Right to try	Early access program
Number of patients treated	Anywhere between 0 and maximum set by resource constraints	Close to maximum set by resource constraints
Transparent criteria for access	No	Yes
Ability to implement fairness considerations	No	Yes
Transparent charging structure	No	Yes
Systematic collection of real world data	No	Yes
Ability to include patient groups in design	No	Yes

Fairness, Transparency and Responsibility in Organ Allocation

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Since organ transplantation was first developed as a treatment option for organ failure there has been a mismatch between the number of patients needing organs and the number of organs available. This mismatch has persisted over time and is a feature of all organ transplant systems irrespective of their consent model – opt-in, opt-out or mandatory choice – and irrespective of whether the system allows monetary compensation to organ donors or the families of dead donors. The mismatch is likely to increase as the indications for organ transplants continue to widen and bridging technologies become available which enable very ill patients to be stabilized and maintained while they wait for a transplant. This means that organs are a scarce, non-fungible resource and that allocation decisions have to be made concerning which of the many patients who need an organ should have priority when an organ becomes available. For life-saving organs, allocation decisions will inevitably mean that some patients receive organs and have their life extended, whereas others never receive an organ and die as a result of organ failure.

This paper will analyse and discuss the ethical implications of a range of possible organ allocation criteria, and will in the light of the recent implantation of a porcine organ in a human being also discuss potential problems for organ allocation in the future.

GEN-Ethics: What do Norwegian women think of utilising genetic testing as part of breast cancer screening?

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Introduction This project aims to explore the balance between personal autonomy and benefits for society. We wanted to identify potential ethical challenges of introducing genetic testing to a public cancer screening program by exploring women's reasons to participate in BreastScreen Norway (BSN), as well as their attitudes to genetic testing. BSN has screened for breast cancer in average-risk women aged 50 to 69, for 25 years, using mammograms (x-ray images) as the screening test. Critics say that breast cancer screening leads to overtreatment, therefore we propose genetic testing as an extra screening test. Genetic testing is a relatively new technology

that generates novel health information. However, there is presumed scepticism among health professionals, authorities, and the general population towards this type of genetic information. Implementing genetic testing in BSN would require a policy change and a revision of the Norwegian Biotechnology Act. This act intends to restrict the Norwegian people's access to genetic testing, by protecting people from harm inflicted by disclosed health information. Unfortunately, it leads to violating people's right to exercise their autonomy. Thus, exploring women's reasoning for participating in BSN would help determine whether genetic testing could benefit public health.
Method This qualitative study comprises interviews with 21 women aged 52 to 70 years old, participating in BSN. A semi-structured interview guide was geared to cover their reasons for participation, their attitude to disclosing health information, and how introducing genetic testing may affect their attitude to screening
Result We found that most women participated because they knew the importance of discovering breast cancers early. However, their attitudes to genetic testing differed, comprising three groups. The first group was not worried about genetic testing and wanted to include it in BSN if possible, to improve the results from the screening. The second group of participants were indifferent and would participate if public health advice recommended it. The third group of women were opposed to the use of genetic testing, either because of their lack of knowledge concerning genetic testing or they had reflected on this issue and declined such testing because it discloses information they do not want.
Discussion Knowledge of genetic risk continues to improve, however, genetic testing is not available for women using BSN. There is reason to develop a more precise breast cancer screening program by including genetic testing in addition to the standard mammography test. Generally, protecting people from potentially harmful health information is the reason for withholding the test. The women who want access to this sensitive health information ought to have it, as their right to make autonomous choices where information is available and usable for preventative measures. Therefore, we recommend that breast cancer screening with an additional genetic test to be voluntary, because a mandatory inclusion of genetic testing in BSN, may risk excluding women who oppose genetic testing, from utilising BSN.

Open Data Policy and Biobank Research – Some Implications for Informed Consent
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In the context of biobank research, where data sharing and secondary use of research data form some of the most basic principles of research policy, requesting informed consent from biobank donors gives birth to a research ethical puzzle. If at the time of consent a donor cannot be given information about all future uses of the data gathered of her, then the consent provided is based on deficient information thereby putting the validity of the consent into question. Currently, the standard form of consent in biobank research is *broad consent,* which has been criticized for its inability to attain valid informed consent. As a result, in recent years, there has been a proliferation of various kinds of informed consent forms: *open consent, meta-consent, tiered consent* and *dynamic consent,* to name a few. Common to all these proposals is that they seek to answer the question of *how* best to inform the donor so that she would be in the position to provide valid consent to biobank research. I demonstrate that the merely technical solutions put forth so far have far from solved the problem of informed consent by sidelining the informational content of consent. I do this by showing that the current practices fail to inform the donors on the most relevant aspects regarding their decision making to donate tissue samples for research. I argue that for informed consent to be morally transformative, the donor ought to

have provided with information on and she ought to have understood what is at stake for her when she provides consent to biobank research.

Should you only do it for free? Why it does matter who pays for an ethics consultation?
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Constructive cooperation with the pharmaceutical companies is a challenge for bioethicists. We need to find out how to preserve integrity on one hand, and how not to fuel conspiracy theories about the big-pharma on the other. During my talk, I am going to address questions such as: Why are conflicts of interests an important risk factor? What is the role of trust and impartiality in the relations with the pharma industry? Is money from the pharmaceutical industry "tainted"? I am going to discuss three models of cooperation with the pharma industry along with their pros and cons - (1) working inside a pharmaceutical company, (2) being a member of an advisory panel (co)funded by the pharma industry and (3) giving advice pro bono as an external and fully independent expert.

The legacy of eugenics in the post-war period in socialist countries
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The history of eugenics was written with an Anglophone accent. The dominant story is like a WWII movie where scientists are British, enthusiastic supporters are American, ruthless politicians are German Nazis and the screenplay is written by the ELSI department. The claim that eugenics started with Galton's ideas in 1883, is easy to defend, but whether eugenics really ended with the disastrous ruins of the racial hygiene program of the Nazis after 1945, is much more contested. Moreover, the historical writings about eugenics were proliferating beside these national "borders" and periodization that were opening a variety of interpretative perspectives beyond scientific racism and genocide. Since the 1960's, eugenics themes were coming up in different socially contested segments of human gene technologies, like reproductive politics, transhumanism, reprogenetics and fertility services, genetic testing, screening and counselling. Both geneticist and historians attempted to demarcate the old from the "new eugenics", but there were clear signs of historical continuity at least till the 1980', which were hard to argue away.
Considering eugenics from the above-described perspective, we have more than enough reason to be cautious when using eugenics as a concept. As Lene Koch argues, "the witless reference to 'eugenics' with no further specification is empty and more often a function of our own projections and intentions than a reference to history." Certainly, it demands a reflective awareness on the diversity of meanings eugenics seems to offer for a variety of audiences. As a first step we need to map these meanings of eugenics, describing the relationship between these concepts. What does "original", reform or backdoor, liberal eugenics means and relate to each other as these meanings are often presented as opposites and used as tools for demarcation efforts (totalitarian versus liberal, pseudo-science versus real science etc.).
Then, if we turn our focus to Eastern European countries, we find a weaker political and scientific institutionalization of eugenic discourse. Still, it could be argued that eugenics was used as a powerful political tool in constructing ethnic identities and supporting nationalist agendas prior to WWII. Based on a historical-conceptual analysis of eugenics the paper addresses the following questions: How can we approach eugenics in the post-war period? It

what sense can we talk about eugenics under socialism? Can we identify practices that could be put under the eugenics umbrella, and in which sense? What was the ethics of socialist biopolitics?

Precision medicine from the margins: standpoint epistemology and risks of epistemic injustice in precision medicine

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Precision medicine is a novel, data-driven approach to biomedical research and clinical care. Inspired by systems biology it presents a holistic, individualized, preventive and person-centered approach to medical practice. While this new 'era' in medicine is still emerging, it has already been broadly discussed in the bioethical literature. Bioethical inquiry in precision medicine exists mainly across the principlist lines set out by Childress & Beauchamp (2013): autonomy, nonmaleficence, beneficence and justice (Erdmann et al. 2021; Salari and Larijani 2016). In this paper I suggest a novel conceptual framework for highlighting bioethical and methodological issues in precision medicine: standpoint theory.

Standpoint theory is a feminist approach to philosophy of science, epistemology, and (scientific) methodology. SPT defends two related claims (Intemann 2010). Firstly, standpoint epistemologists assert that knowledge is (socially) situated and therefore inherently partial (Harding 1991; Haraway 1988). Second, it argues that knowledge from subjugated standpoints has an epistemic advantage. The standpoints of marginalized or oppressed groups are "less partial and distorted" (Harding 1991; Wylie 2003). Accordingly, SPT compels us to start research from the margins, direct our gaze towards the perspectives, and lives of marginalized groups. This appeal is not only morally but also epistemically warranted; including these perspectives, Harding claims, leads us towards 'Strong Objectivity' (Harding 1991).

SPT has already earned its stripes in a myriad of disciplines within the sciences (f.e. see Schiebinger 1999, Wylie and Sismondo 2015 and more recently Friesen and Goldstein 2021). However, it is yet to be applied to the context of precision medicine. I propose a dual approach to applying standpoint epistemology in precision medicine. I show, using the approach of standpoint theory that, first, precision medicine is based on a situated and partial perspective of health and disease which it portrays as objective and holistic (Vogt, Hofmann, and Getz 2016). Second, I show that the operationalization of these dominant concepts leads to novel issues of epistemic injustice unique to precision medicine.

Building on the work of Miranda Fricker (2007) and, more specifically, Ian James Kidd & Havi Carel's application of epistemic injustice in healthcare (Kidd and Carel 2017; 2019), I propose the epistemic commitments of precision medicine might give rise to entirely new forms epistemic injustice that could significantly impact the patient-doctor relation. As an example, I show that precision medicine runs the risk of exacerbating testimonial injustice in healthcare. The objective, holistic and data-driven approach to disease might lead to a credibility excess (Medina 2011) for health data and algorithmic decisions. I claim that as algorithmic authority (Crompton 2020; Jongepier 2020) gets a seat in the doctor's office, the patient must compete for epistemic authority. This is problematic for precision medicine as a project. If it wants to fulfil its promise of being a patient-centered approach to clinical care issues of epistemic injustice need to be amended.

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Bioethics in Pharma: Lap Dog, Show Dog, or Service Dog?

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Bioethics scholars have divergent views about working with industry. Some regard any connection as inherently tainted; others seek out consulting arrangements (or even full-time employment); still others make case-by-case decisions if approached. My talk will examine the moral dimensions of relationships between bioethics scholars and pharmaceutical companies. Can we avoid being lap dogs, overly influenced by the power that the industry wields? Can we avoid being show dogs, held out by companies as proof of their virtue? Can we succeed as service dogs, providing meaningful input that pharma values appropriately and uses well?

eHealth components and interpersonal relationships in health care – a paradigm shift? A scan for traces

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Electronic Health (eHealth) should not only help to make medical care more efficient, but is also intended to offer improved, individualized and personalized solutions for patients. While some people have high hopes and expectations for the digitalization and datafication of medicine, others fear a profound, disruptive change, which is manifested, among other things, in shifts within the health-care provider-patient relationship [1;2;3]. The aim of our research is to trace this paradigm shift using the example of a newly implemented care model for allogeneic SteM cell transplantatIon, faciLitated by eHealth (SMILe), by visualizing the actual impact of datafication on patients*, health-care providers* and their respective relationship structures.
The SMILe care model provides additional support by an advanced practice nurse (APN) and an eHealth component. The eHealth component consists of the SMILeApp, allowing patients to transfer health data daily to the APNs which, in turn, can check it due to a remote-monitoring system software (SMILeCare).
In order to reach the aim, semi-structured qualitative patient interviews (N=12) were conducted. The data analysis was done by using an inductive thematic analysis and the framework method. In addition, a 2-year project monitoring with selective ethics consultations in the multidisciplinary team was designed and implemented.
Based on the measures carried out, it can be shown that a paradigm shift is indeed taking place. However, not in the expected way. Among other things, it becomes clear that datafication is capable to make patients more visible to health care providers. Regular feedbacks on the health data increased the contacts and thereby patients felt cared for. They reported on an intense relationship which was also experienced by the APNs. In addition, the datafication provided security and structure, which is expected to have a positive influence on patients' self-perception. Moreover, APNs submitted valuable diagnostic information to the physicians, which was highly regarded. This significantly increased the professional esteem of APNs on the health care team. raised considerably. Thus, we conclude that the data obtained is a resource that provides an upgrade of the care staff vis-à-vis physicians.
Overall, it can be concluded that within the SMILe care model, datafication does not necessarily lead to alienation and depersonalization. This seems to be owed to two facts in particular: First, the technology was developed and implemented with recourse to a user-centered approach. Second, and this seems to us to be an important factor here, the technology was not developed to replace human contact in aftercare, but as an additional module to support and complement the personal work of the APNs.

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The spectre of paternalism haunts the shared decision making: a qualitative study on patient's refusal of long-term dialysis in Taiwan

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Objectives: Shared decision making (SDM), as a common ideal for the physician-patient relationship, emerged as the movement from a paternalistic approach to that in which patients have the right to share in decision making. However, no existing local study examines whether this ubiquitous concept successfully helps physicians to relinquish their paternalistic communication practices. Focusing on patients' refusal of long-term dialysis, this study aims to reveal (1) physicians' understanding of SDM, as well as the features of their communication strategies, and (2) the patients' concerns about long-term dialysis and the logic of their decision-making process.

Methods: We conducted in-depth, semi-structured interviews with 10 patients diagnosed with end-stage renal disease (ESRD), each of them refused long-term dialysis after the SDM framework, and 10 nephrologists (9 of them attended the outpatient/ward of interviewed patients) at the Chang Gung Memorial Hospital from March to May 2020. Interviews were audio-recorded, transcribed, and translated from Mandarin to English. They were subsequently analyzed using thematic analysis.

Results: For physicians, a major aim of SDM is ensuring patients have the right to make medical decisions for themselves; meanwhile, to reduce medical paternalism. However, several paternalistic features were identified in current SDM implementation. First of all, when employing SDM, physicians anticipate a rational but compliant patient. Then, they regard communication as successful in cases where patients comply with their medical advice. Moreover, physicians describe patients who refuse long-term dialysis advice as lacking insight, not paying attention to personal health, or misunderstanding the treatment due to thinking in a non-medical way. To attain "well conducted" SDM, physicians tend to take persuasive communication strategies, including referring to various medical evidence, and seeking help from patients' family and other health instructors.

Nevertheless, our interviews revealed patients do think differently from physicians but they are overlooked by physicians. Apart from medical considerations, the following concerns were identified in patients' deliberation: (1) practical concerns, including financial burden and care needs, (2) psychological concerns, such as mental unreadiness, and the worry of becoming the "abnormality", and (3) physical concerns, which mainly cover the impact of symptoms on daily life. Additionally, patients experience the decision-making process as iterative in contrast to physicians' linear decision-making process, which proceeds from neutral facts to direct decisions. Patients would keep evaluating and weighing up the disease, treatment, and their life, in which they consider their social context and current physical condition to make the most appropriate decision at the moment of the patient-physician encounter. Ultimately, the majority of patients didn't regret deferring long-term dialysis, even though most of them underwent painful and risky emergent dialysis.

Conclusions: Although SDM has been widely promoted in Taiwan, by revealing physicians' understanding and implementation of SDM, we argued the paternalistic mentality covertly manifests in subtle aspects under the cover of SDM. Conclusively, we suggest physicians countering their paternalistic mentality and communication practices through taking patients' multiple concerns and iterative decision-making logic into consideration to actualize the spirit of SDM.

Beyond biopolitics: the importance of the later work of Foucault to understand care practices of healthcare workers caring for undocumented migrants

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In many European and North-American countries, undocumented migrants have restricted access to public healthcare services. Healthcare workers in these services face many ethical concerns and professional dilemmas due to restricted healthcare access. They are forced to decide if, and to what extent, they grant access to resources that are officially reserved for citizens. This dilemma has mostly been theorized as a conflict between human rights and deontological norms on the one hand, and legal and institutional requirements on the other. In the medical humanitarian sector, efforts focused on alleviating suffering of undocumented migrants can become instrumentalized to control and govern migration flows. These ethical concerns related to humanitarianism have mainly been theorized through the lens of biopolitics. This article concerns healthcare workers who regularly take care of undocumented migrants in Belgium in a context of limitations in their healthcare access, both in the public sector and in the medical humanitarian sector. Based on semi-structured, in-depth interviews and ethnographic observations with healthcare workers, we explore how they ascribe meaning, reflect upon and give shape to their care practices in these dilemmatic situations. We interpret the accounts given by the healthcare workers through the lens of Foucault's later work on care of the self.

Healthcare workers in clinical roles experience a certain degree of freedom in relation to the existing limitations to healthcare access of undocumented migrants. We found a range of practices that enabled health workers to relate in an ethical way to the existing limitations in healthcare access. The respondents developed techniques to guide the attention away from the undocumented status, to master their affective responses and to transforms their bodily attitude towards undocumented patients. These comprised of practical mental exercises to remind oneself of one's role/position in the wider healthcare system and one's commitment to treat all patients equally. The respondents described these as a learning process, inspired by colleagues who function as role models. They also attribute aesthetic qualities, such as excellence and excitement, to practicing a minimalistic kind of medicine.

These findings show the value of care of the self as a concept to understand care practices of healthcare workers to undocumented migrants. It offers a framework for understanding ethics in a way that is somewhat independent of the traditional professional ethics and formal codes of ethics. Moreover, these findings nuance biopolitical analyses of healthcare to migrants, conceiving of healthcare workers as merely being obedient instruments of humanitarian government.

Responsibility and moral diversity in IT-based decision support systems

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IT-based Decision support systems have been established in healthcare for decades. However, they are becoming increasingly important for digitization of healthcare. Especially against the backdrop of artificial intelligence they propose a solution of individualized medicine, that with the help of these systems and individual medical information about patients-in diagnosis or therapy- decision could be supported evidence-based and as precise as possible. But the algorithmic prediction relies on a big data approach or a rule-based approach, which refer to familiar, but also newer ethical challenges.

This entails an ethical investigation of such systems, especially with regard to one of the main ethical categories: responsibility. Responsibility as one of the central principles of ethical debate on technology can be regarded as a key criterion against the background of promoting an optimized diagnosis and therapeutic approach with at least a consistent quality of life for the individual patient. This involves various partners in the development and application processes of decision support systems, where at least five parties are part taking: researchers, developers, distributors, users and affected persons.
Against the backdrop of a relational concept of responsibility, the issue of moral diversity takes on special significance and points to the challenge of the circumstances surrounding the assumption of responsibility.
This is where moral diversity becomes a challenge for decision support, because it counteracts the moral acceptance of responsibility by initially logically undermining the assumption of a common standard through moral diversity.
First, for example, moral diversity can lead to different outcomes of decision support systems due to a biased algorithm. This is especially foreseeable for algorithms that have been categorized and trained by appropriate personnel especially scientific staff, or that are rule-based. Depending on the ethical and moral orientation, different results may occur that the staff member is not aware of as moral preconceptions. Secondly, the focus on the decision making between healthcare professionals and patients and their relatives proposes a challenge due to the different moral standards of the participants and as well as their assessment of the decision support systems outcome. Finally, it is necessary to stress the challenge of the patients' unreflective acceptance of the outcome and the resulting decision, which does not consider different moral concepts.
Given these challenges of moral diversity in the context of accountability in decision support systems, at least a common minimum standard for IT-based decision support systems and their outcome generation needs to be agreed upon, as well as raising awareness among all related parties regarding technical processes. At the same time, it is particularly important to involve those directly involved in the decision-making process in a shared-decision-making process on an equal footing, so that responsibilities for the final decision can be carried morally together.

Diversity of ethical perspectives in medicine 4.0 – A project report
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In this contribution, we anticipate the results of the research project “Medicine 4.0 – the ethical basis of digitalization in healthcare” funded by the German Ministry of Health, which investigates the ethically relevant effects of digitalised medicine using mobile health and telemedicine as prime examples, with the final aim of deriving policy-relevant overarching recommendations. Within this work, we focus on the two areas of medical and health-related apps as well as telemedicine with a special focus on telemonitoring. In an iterative interdisciplinary approach, we link social science research with analytic research on the ethically relevant effects of these technologies, including on the doctor-patient relationship, the relationship between responsibility and solidarity in healthcare and on the autonomy of the individual.
In both the ethical and social science research, a key focus concerns the identification and analysis of an apparent diversity of stakeholder values and perspectives. In mobile or mhealth, which we concentrate on for this presentation, technology developers, insurances, physicians and public health professionals as well as ‘patient-consumers’ need to be looked at and involved. Their outlook in turn may converge, but also be in tension or collide, e.g. regarding

conditions for data access and use, liability in case of malfunction or misuse or implementation as well as integration into the health system.
We look especially at the different and hypothetically shifting (professional) roles of the stakeholders influenced by digital technology and their perspective towards certain social changes and their value-based interpretation of (wanted, necessary and/or inevitable) changes in healthcare and beyond. In our presentation we will show in an exemplary way based on the results of our empirical mixed-methods study how these processes and effects evolve and may influence ethically relevant questions. We also reflect on methods that are helpful and reasonable to analyse new and changed questions in this field.
Overall, we outline a systematic approach for understanding, evaluating and governing this complex arrangement in healthcare as a public and private matter. Diverse ethical perspectives should be integrated to fully capture the relevant issues that extend beyond medical ethics to, amongst others, business and public health ethics. Here, we highlight issues concerning data quality and safety, autonomy of individuals and shifting conceptions of responsibility for health. The research combines ethical insight and expert stakeholder perspectives on the most pressing issues in this fast-moving field. Further, traditional issues such as informed consent, confidentiality and the role of individual autonomy, are in part redefined with the emerging role of automated or algorithmic decision-making.

Normative Metaphysics and the Definition of Death
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Disagreement over the definition of death and its criteria for determination can often be traced back to disagreement over how parties in the debate use terms like “organism,” “human being,” “person,” “death,” and “irreversible.” Proponents of different views often claim that their use of these terms best captures the reality of the phenomena in question, and they may offer a broader metaphysics to back up their claims. Metaphysicians, of course, are interested in the nature of reality. However, if a pragmatic issue over which individuals we declare dead gets bogged down in disagreement over alternative metaphysical views, it may lead to thinking that the issue is either unresolvable or that no consensus could ever be reached. Amy Thomasson, however, has suggested that metaphysicians can play a normative role by helping to decide which concepts or conceptual scheme we *should* adopt. Through an analysis of how these terms have functioned in the debate over the definition of death and what rules for the use of these terms best serve those functions, I make recommendations for how the terms *should* be used with the aim of trying to achieve consensus among disparate parties in the debate.

Accessibility of healthcare services as a relational concept
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The standard understanding of accessibility of social services, such as healthcare, relies on rules, laws, and institutions. It sees the potential users of such services as independent and self-reliant individuals whose relations to others are of secondary importance. In effect, such an approach does not appreciate the relational nature of human being. Who and what they are is determined by their relations to and with others, and so what they do and what services, even if they are available to them, they use depends on those relations. Accordingly, as long as human relationality remains unappreciated and unarticulated, it will be extremely difficult to gauge the

extent of the overlap between the actual accessibility of services and that defined by various rules, laws and institutions.
This talk will explore the potential of a relational view of accessibility of healthcare services as a measure of their actual accessibility. It will be proposed to determine accessibility of healthcare services on the basis of the social relations, in particular the relations of power, in which the potential users of the services are embedded. By focusing on those relations one can identify the contexts which determine accessibility of healthcare services and the individuals and groups with unequal access. In effect, the relational approach to accessibility of healthcare services does not have to rely on a catalogue of limitations of accessibility and underprivileged groups. By identifying the relations which determine the actual accessibility of social services, this approach is open to social diversity and helps appreciate relational causes of vulnerability and marginalization. It can also help identify those of us whose access to healthcare is less than equal, without relying merely on those forms of vulnerability and marginalization which have been socially recognized.

The Transplant Patient, Personal Identity, and a Good Life
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I will discuss the challenges faced by transplant patients in their thinking about their view of a good life. Taking the experience of illness as the point of departure, I will focus on the disruption a serious disease produces in a person's life and the consequences of this disruption for the continuity of their life experience and sense of identity. A sufficient level of bodily functioning and integrity are not only constitutive of the patient's recovery but also necessary for the experiential continuity of their self and their ability to design their own view of a good life. Discontinued experience turns a person's life into a collection of unrelated episodes rather than a meaningful whole, loss of meaning being a major cause of erosion of a good life. Next, I will discuss the impact of a transplant on the patient's potential to develop a viable view of a good post-transplant life for themselves. The presence of someone else's organ in the patient's body, recurrently brought to their awareness by the demands of the immunosuppressive therapy, questions the integrity of the bodily foundation of the patient's view of a good post-transplant life. Additionally, the dependence of the functioning of the patient's body on immunosuppressive therapy reveals the fragility and insecurity of their bodily make-up and their future. Thus, the transplant patient's potential to develop a stable and viable view of a good life for themselves is repetitively challenged. Drawing on the preceding observations, I will elucidate the challenges inherent to attempts at integration of the patient's fragile bodily integrity into their view of a good life for themselves. I will claim that transplant patients must not only integrate the fragility of their bodily make-up and insecurity of the continuity of their experience into their view of a good life. They must also include the recurrent reexamination and possible redesign of their account of a good life into that very view.

Conflicts between patient wishes and health practitioner duties: the case of transplant tourism into China
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The European Parliament, the US Congress House of Representatives, the Czech Senate and Canadian Parliament House of Commons Sub-committee on International Human Rights of the

Standing Committee on Foreign Affairs have all passed resolutions expressing concern over persistent and credible reports of forced organ harvesting of prisoners of conscience in China for transplantation, with primary victims the practitioners of the spiritually based set of exercises Falun Gong. An independent tribunal in June 2019 in London UK concluded that this abuse was happening with Falun Gong victims beyond any reasonable doubt.
A patient in need of a transplant on a local waiting list for a long time, tells his/ her health practitioner, that he/ she can wait no longer and is going to China for a transplant. What should the health practitioner do?
In particular, should the local health practitioner give or refuse to give the patient his/ her medical records on request? Should the local health practitioner prescribe or refuse to prescribe continuing medication for the patient? Should the local practitioner write or refuse to write a letter about the current condition of the patient, diagnosis, prognosis, current medication and recommended treatment? What, if any counselling, should the health practitioner provide to the patient?
A patient returns from China after having received a transplant there, and needs continuing after care. Under what circumstances, if any, should the health practitioner give or refuse after care?
Legislation is being proposed to require health practitioners to report to health authorities transplant tourism into China. Should health practitioners support or oppose compulsory reporting which would require an exception to the principle of health practitioner patient confidentiality?
The presentation would be to attempt to address these questions. Transplant tourism into China often generates a conflict between the interests of patients and the interests of the transplant source victims where health practitioners are caught in the middle. The question becomes how best for health practitioners to navigate this middle ground consistently with ethical principles.
The questions here are not just theoretical. Transplant tourism into China is real and significant. Many health practitioners in several countries have had to address these questions. The presentation would set forth the experience to date, present how these questions have, practically, been answered and evaluate the responses.
The overall conclusion would be that there are significant gaps in the global bioethical structure dealing with these issues. A direct consideration of the issues faced and the responses in various countries can suggest ways in which these gaps can be filled.

The race for public trust: is public engagement the solution?

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Many stakeholders call for public engagement as a mean to enhance public trust. Activities that involve citizens have even become mandatory to obtain some forms of EU funding for research, innovation and implementation. For example, public engagement is an important activity within the joint action ‘Towards the European Health Data Space’, which aims to prepare the EU member states for the development of a European health data sharing infrastructure. This activity was called ‘Healthy Data: your views on the reuse of your health data.’ Its goals were to inform the public and to gather opinions on the secondary use of health data and how citizens should be involved in this future framework.
It is often assumed that the correlation between public engagement initiatives and public trust is a given, and that engaging the public is an effective mean of enhancing trust about political decisions and the way they are made. Through our project and research, we demonstrate that this link is not as evident as expected.

First, this correlation lacks a conceptual foundation. Public trust is a tricky concept with multiple definitions, each of them entailing different aspects. Therefore, one might wonder what is to be enhanced exactly. Stating that public engagement will enhance public trust might also skip what it can do in the first place, which is identifying the factors that influence and even constitute it.
Additionally, the assumption that public engagement enhances public trust might also miss the procedural complexity of running broad scope engagement initiatives. The first obstacle for instance being public interest in the topic, no matter how important the political decision can be for our society. This public interest might not only be linked to the final decision that will be made, but also to the process itself and the possibility to be engaged in policy-making processes. Thus, how citizens envision their role themselves can be an important topic in a citizen engagement project.
Finally, even when successfully accomplished, such correlation may undermine the finality of public engagement. While it might affect in some way public trust, it should not be seen only as a means to enhance it, but as an end in itself: to allow the public to actively participate in policy-making. Moreover, structural public engagement could replace the need for public trust. As the former involves full transparency, active information and sometimes even the development of concrete policies, it could bypass the leap of faith that makes up the latter. If engagement activities enhance trust, it is because citizens realize why they are trusting or because changes are made based on citizens' needs and values. Enhancing trust will often be a by-product of good public engagement, but good public engagement projects should never set the goal of enhancing trust.

How do citizens experience vulnerability in genomics?

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In the context of healthcare, and more specifically in genomics, the concept of vulnerability has been studied principally for particularly vulnerable groups and from the perspective of patients in the clinical context. However, the growing influence of genomics, especially the potential implementation of genomic screening programs in healthy populations, may generate more fundamental and shared vulnerabilities among the general population.
This reflection emerged from the DNA debate, an online public engagement initiative in Belgium, where 1127 citizens expressed 1258 opinions about ethical issues related to the use of genomic information in medicine and society. The inductive qualitative analysis of these contributions let uncertainty, distrust, fears, and lack of security emerge as significant themes, all related to a fundamental core theme of vulnerability.
Participants expressed their *vulnerability in two ways*.
First, genomic testing informs individuals about their *ontological vulnerability*. Every human is unavoidably vulnerable because of the risk (genetic predispositions) of being harmed by constitutional weaknesses such as diseases, anxiety, and mortality. This first vulnerability is exacerbated by the twofold uncertainty everyone is confronted with when doing genomic testing: on the one hand, in the format of the results (probabilities, risks) and, on the other hand, regarding the specific findings of the test.
Second, the uncertainty about how genomic information will be used in the future puts everyone at risk of *situational vulnerabilities*. For instance, our genomic information could one day be used to discriminate against us, causing psychological, economic, and social harm.
These two types of vulnerability citizens experience in genomics influence the ethical framework around the broad implementation of genomic technologies. The ontological

vulnerability should be managed, even if it cannot be eliminated, and there is a societal responsibility to avoid, or at least minimize, situational vulnerabilities in genomics.
Conclusion – key message: Citizens from the DNA debate expressed fundamental vulnerabilities in genomics, bringing new ethical questions and challenges. These should be considered by healthcare professionals, health policymakers, experts, and other relevant stakeholders in genomics to prevent harm and maintain the public's trust.

Trustworthiness of research biobanks: how to build it?
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Background. Trustworthiness is a complex concept (different from reliability) defined by some researchers as "belief about probability of reciprocation" (Chang et al., 2010) or "the counterpart of trust, a characteristic of a trusted person or entity such that it is likely to perform as expected and that it meets the normative expectations of trust" (Nickel, 2011). This concept is more often used in business ethics than in medical ethics or research ethics; however, trustworthiness of medical professionals, researchers, as well as institutions (e.g. research biobanks) is an important precondition for building short- and long-term relationships with patients and research participants.
Methods. The aim of our research project was to contribute to ethically and socially responsible governance of research biobanks in Latvia by analysing attitudes, concerns, trust and needs of the general public, donors and researchers. Methodology of the project combined quantitative and qualitative research methods and included three quantitative surveys (representative survey of general public (n=1000), survey of biobank donors (n=250), survey of researchers who collaborate with biobanks (n=70)) and series of qualitative semi-structured interviews (20 interviews with biobank donors and 20 interviews with researchers). This combination of research methods was used to build a comprehensive picture of opinions. The survey for general public included questions on biobanks from the 2010 Eurobarometer study thus allowing to compare the results.
Results. There were statistically significant differences between results of 2010 Eurobarometer study and 2019 survey regarding willingness to participate in biobank research, type of consent, and sharing samples among EU member states. In 2019, more participants were willing to participate, preferred broad consent, and were positive about sharing data and samples among EU member states.
Analysis of qualitative interviews showed that the most important aspects for building trust relationships between biobank and donors of biological samples are informed consent process and trustworthiness of the biobank and research staff. From the donors' perspective trustworthiness had several meanings: (a) trustful relationships based on transparency of informed consent; (b) personal relationship with a trustworthy person (doctor, researcher, staff member), and (c) trustworthiness as reciprocity, e.g. hope to receive individually meaningful research results.
Conclusion. Trustworthiness of biobank and biobank staff is important concept for all stakeholders, especially for research participants/donors. Building trustworthiness of a research biobank means not only ensuring transparent informed consent procedures and trustworthiness of individual staff members, but also avoiding false expectations regarding the return of individual research results.
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Applying the Dual-Interest Theory: Another Argument In Favour Of Pregnant Women's Autonomy

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In their influential work *Family Values: The Ethics of Parent-Child Relationships* (2014), Harry Brighouse and Adam Swift develop a novel account of why families are valuable. They argue that the existence of the family can be justified insofar as it produces 'familial relationship goods'. These goods are such that they generally meet the interests of both children and parents in better ways than other child-raising constructions likely would be able to. The interests of many adults are met by a parent-child relationship because parenting is part of what a fulfilling life means for them. When it comes to the interests of the child, they argue that only the family, in which a small number of people raise children, allows for the particular kind of relationship between children and adults that is able to deliver what children need. Crucially, this relationship depends on love and discretionary authority: "For a child's interests to be met, she needs to be cared for by at least one adult who loves her, the loving relationship needs to be sustained over a long period, and the adult who loves her must be able to exercise a good deal of discretionary authority over her" (Brighouse & Swift, 2014, p. 72).
This paper explores whether the dual-interest theory of Brighouse and Swift can be fruitfully transferred to a bioethical context by applying it to the prenatal stage. It hinges on the idea that discretionary authority of a parent over a child is not only in the interest of the adult, but also in the interest of the child. Brighouse and Swift argue that it is valuable for children to know that their parents think and decide about how to raise them, what to introduce them to and even which bedtime story they read them without too much interference by the state or other institutions. Part of the intimacy of the parent-child relationship comes from the way those involved are able to shape the relationship as they see fit. In this talk, the argument by Brighouse and Swift will first be further explained. I will then apply it to the relationship between pregnant women and their future child and argue that the dual-interest argument may lead us to argue against too much interference with or limitation of the autonomy of pregnant women. This line of argument will be based on the observation from research fields such as epigenetics that many decisions about behaviour made during pregnancy can influence the health and characteristics of the unborn child. A pregnancy that is mostly shaped by following the advice or policy decisions of others, might lack the discretionary authority that women have a right to with an eye on the relationship with their future child.

Moral Knowledge and the Good of Medicine in Diverse Global Contexts

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In this paper, I argue that an epistemology of the nature of goodness can inform our knowledge of the good of medicine in order to aid in the resolution of health care disputes in a diverse global context. First, I offer an account of moral knowledge resting on a metaphysics of the

nature of goodness which seeks to show the identity of being and goodness. I argue that from direct empirical experience, through phenomenological reflection, it is possible to know that goodness and being are identical. Second, I show how the convertibility of being and goodness can apply directly to the particular good of medicine. I argue that since medicine as a human activity exists, it is also objectively and really good. Third, I offer an application of how knowledge of the good of medicine can apply in diverse global contexts in health care decision-making where there is disagreement about the fundamental goals of medicine. In this section, I consider several case studies which capture the ideas developed in this paper. The case studies illustrate how objective knowledge of the good of medicine can ameliorate healthcare disputes in a globally diverse context.

Disagreement on death and what to do about it?

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In 1968 the *Journal of the American Medical Association* published the report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death titled "A Definition of Irreversible Coma". The report suggested that death should be understood in neurological terms as irreversible cessation of all brain activity. Nowadays this whole brain criterion of death is almost universally accepted criterion that is used by physicians all around the world. However, almost since the time of its introduction this conception has been attacked from at least two different sides. Some authors have argued that the whole brain criterion of death is philosophically indefensible, and we should go back to the good old heart and lungs criterion of death. One the other hand, several authors have argued that the whole brain death criterion doesn't track the concept of what does it mean to be dead in the sense that is relevant to self-conscious or conscious beings. They argue that we should be considered dead as soon as we irreversibly lose the capacity of having conscious states. As a result, one prominent bioethicist described the current situation about the criteria of death in medicine as a condition of "unstable consensus". In my paper I argue that this problem can be solved neither by getting more information about our biology nor by better methods of philosophical analysis. The only feasible way forward from this impasse is to gather more empirical data on how people actually think on this issue. In the second part of the paper I will discuss the existing evidence on the folk conceptions of death and address some practical implications of taking those views into account.

End-of-life Options in Humans and Animals: a Comparison

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Context: End-of-life decisions are common both in human and veterinary medicine. In modern societies, most people are experiencing death and dying of their companion animals before (and more frequent than) attending and experiencing terminal care in dying relatives.
Objectives: Which differences and similarities can be found in end-of-life decision-making in humans and animals? In what way are treatment options and the dying process interdependent between the fields of human and veterinary medicine? What does this interdependency mean for ethics at the end of life in humans and animals? Does a philosophical analysis support the tendencies of an assimilation of medical and veterinary ethics?

Results: There is a strong tendency in veterinary medicine to adopt life-sustaining and life-prolonging treatment options for seriously ill animals. In the past years palliative care and even hospice care have also been developed and implemented in some veterinary centres. On the other hand, euthanasia is the most common cause of death in companion animals. Treatment decisions at the end of life in pets seem to seek the right moment for euthanasia. In contrast, palliative care in humans is carried on until death occurs. Only few countries in the world legalised the option of euthanasia. Therefore palliative and hospice care usually are the last step in the treatment of human beings. Withholding and withdrawing treatment – particularly on the patient's request – are widely accepted. But in public awareness, options of shortening the dying process are widely approved in companion animals, and are becoming more and more popular in the debates about the fate of human patients. Can the growing support of euthanasia in humans be understood as a result of animal ethics and the idea of euthanasia in companion animals? And if so, which philosophical ideas support or disprove this equation and assimilation? The paper will give evidence for the developments drafted above and will find preliminary answers regarding the comparison of ethics in human and veterinary medicine.

Social diversity as a challenge – equal access to healthcare from the German perspective

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In the society as diverse as Germany, equal access to medical care constitutes one of the main challenges for healthcare. Social diversity in Germany, similarly as in other Western countries, encompasses several different aspects, such as: socioeconomic status, race, ethnicity, language, nationality, sex, gender identity, sexual orientation, religion, disability and age. However, in recent years, due to progressing influx of migrant population, cultural, ethnic, and language diversity comes to the forefront of the issue. Encounters between patients and healthcare professionals increasingly take place in an "intercultural setting". According to the Federal Statistical Office, around 15.6 million people with a so-called migration background live in Germany, which corresponds to around 19 percent of the population. They enrich social coexistence and at the same time pose major challenges for the healthcare system. As reported, people with migration background belong to vulnerable groups with regard to the access to healthcare in Germany. This situation occurs due to several factors, among others due to communication and cultural barriers, social and economic status, education or illegal residence. Cultural competence is a key requirement of our modern healthcare. Successful communication between doctors and health professionals with patients from different ethnic and cultural backgrounds can lead to better health outcomes, improve work efficiency when dealing with patients, increase patient satisfaction and, above all, their quality of life. In a health care system based on solidarity, all patients should have equal access to medical services. However, in an increasingly pluralistic society, significant ethical challenges can arise. Therefore, from the ethical perspective, several questions regarding equal access to healthcare for people with migration background are paramount and need to be asked: What should culture-sensitive medicine and corresponding medical ethics look like? What are the consequences of this for improving medical care for patients with a migration background? How the relationship between solidarity and personal responsibility should be determined in the context of cultural diversity and health? Should there be special patient rights for patients with migration background? Which health policy steps are necessary in this context?
In order to cope with a heterogeneous patient population and to achieve a high standard of medical care, an advanced strategy is required to tackle the challenges posed by diversity in the healthcare system. The first step for an effective strategy is to look at the obstacles and

opportunities to deal with diversity in the healthcare system and to put solution strategies up for discussion. During the presentation, points for such discussion will be provided from the ethical perspective in context of German public healthcare. Special attention will be paid to the question of dealing with cultural diversity in the clinical setting, especially to the concept of so called Medical Diversity Management. On the basis of several case studies, presented will be examples of the major ethical challenges confronted by healthcare professionals in a situation of multicultural encounter.

Religion & End-of-Life Healthcare: Accommodating Differing Values, Norms and Ontologies

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Healthcare near the end-of-life is complicated by communication and knowledge gaps between patients, clinicians, and families. These gaps also feed into moral uncertainty, and at times moral conflict, among these decision-makers. When religious beliefs and values are added to the mix, conflicts often intensify and communication gaps seemingly widen. This presentation will draw upon leading patient-doctor communication models, and best practices in clinical ethics consultation, to provide a practical ethics framework through which to address such challenges by increasing understandings the moral valences of actions and decisions. The three-step approach calls for (i) discovering the meaning and values ascribed to living and death, (ii) considering norms and constraints upon biomedical practices and communities, and (iii) negotiating and accommodating both the actions and non-actions taken by clinicians, individuals and families. Accordingly, the first step involves examining religious ontologies, the second step religious ethics and healthcare laws and policies, and the third involves deliberative action. Three cases of religious conflict near the end-of-life will illustrate the framework in action and reinforce the merits of the approach.

Global Bioethics: “Back to the Future”?

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A broad vision and an interdisciplinary approach have characterized the birth of bioethics, in order to foster dialogue between the various professional fields and the entire society, also, outside the academic context. But certain expectations have been disappointed, or went, in part, unfulfilled: bioethics was substantially "swamped" within the academic sphere, losing much of its "prophetic voice" and capacity to stimulate the scientific and social commitment. Bioethics often tends to act as justification or regulation of scientific developments and of cultural changes, rather than being a critical voice capable of accompanying and not only trying to catch up with such developments and changes. The "bridge to the future” seems to have somehow tilted, and perhaps needs to be restored and expanded, with greater care and responsibility in crossing it. The need for broader horizons emerges, in particular taking into account the process of globalization and the growing relevance of socio-economic-environmental factors in the context of health and medical responses and the principles of justice and solidarity, as it is recovering and developing "global bioethics", for the survival of humanity and the entire planet. The dynamic of globalization, in pluralistic societies both from the cultural and religious point of view, asks urgently for a common ground where an interdisciplinary dialogue and shared decisions can be made. Human rights seem to have the suitable features to be common point of

reference for this ethical task. Following the indications of V.R. Potter and the developments proposed by Henk the Have, it is important and urgent to develop global bioethics to reaffirm some general ethical principles and support local actions for social justice and environmental sustainability, promoting the health of the whole person and all people.

Ethicists into the lab – once again? How to conceive of a sound practice turn for bioethics

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Organoids are still rather new bio-objects that triggered an ethical debate with strong similarities to ethical discourse on stem cells, biobanking etc. There is one proposal for methodological improvement, however: to integrate ethics closer into scientific practice, whether in the form of ethics in the laboratory (see Cepelewicz 2020), "engineering ethics" (Hyun 2017), "real-time ethics engagement" (Sugarman/Bredenoord 2020) or "ethics parallel research" (Jongsma/Bredenoord 2020).
In this paper, I investigate the proposed practice turn by reviewing concrete methods of closer engagement with scientists brought forward by the contributors to the organoid ethics debate and by discussing their possible implications for ethical theory and practice. The focus will be on conditions for engaging with scientific practice in a meaningful way. I'll argue that closer engagement with science needs to be complemented by taking up approaches and findings of social studies of science and philosophy of science. Both provide relevant resources for making sense of science as social practice in contrast to a still lingering idea of science as being largely separate from society and of being of ethical concern mostly with regard to its applications and downstream effects (Hilgartner et al. 2017). Whereas social science research opens up the blackbox of the manifold societal conditions and dimensions of scientific research where norms and values are inextricably linked to specific practices, institutions, thought styles etc., philosophy of science provides tools and insights for understanding the dynamics and theoretical underpinnings of scientific research such as the role of models or cell concepts (Fagan 2020) in organoid research or the situatedness of knowledge more generally (Haraway 1988). These theoretical and societal aspects are crucial for identifying ethical issues related to the biosciences and for understanding current transformation processes of which science, society and ethics are intricately intertwined parts. They tend to be blanked out by bioethicists as well as by scientific practitioners though. The paper ends with some preliminary thoughts about how societal and epistemological issues could be integrated into philosophical bioethics and its engagement with scientific practice.

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Does Complementary and Alternative Medicine correspond to ideals put forth in Medical Humanism?

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Modern medicine is highly developed and offers good care for many people. However, patients are often dissatisfied with the way they are treated by physicians, hospitals or at home when they are dependent on the help from healthcare professionals. Also, physicians, nursing staff and other medical professionals complain that their working conditions have changed negatively. In sum, there is the impression that the health care system is becoming increasingly inhumane. This leads to a debate about what constitutes quality health care.
A discussion of how a good and patient-oriented medical care should look like can be found in literature about so-called *medical humanism*. As there is no consensus about the exact meaning of this term, we define *medical humanism* as an ethical theory consisting of specific values for health care professionals, especially physicians. This includes in particular: dignity, autonomy and patient empowerment, empathy, holistic nature, individuality and humility.
These are also values that especially providers of *complementary*, *alternative* and *integrative* medicine ("CAIM") often advertise. Therefore, patients may think that they will find in these non-conventional approaches exactly what they are missing in biomedicine. But is it true that CAIM actually correspond (better) to ideals put forth in medical humanism?
CAIM is an umbrella term that encompasses various diagnostic, therapeutic, preventive, rehabilitation-related and mere "lifestyle"-oriented approaches, which makes it difficult to generalize all observations. Nonetheless, a closer view reveals that there are legitimate doubts regarding the unqualified truth of the hypothesis that CAIM is, in Western societies, tendentially better able to conform to the values of medical humanism than established biomedicine.
CAIM, generally spoken, can conform to values of medical humanism such as individuality or empathy. But already the often advocated hallmark of CAIM, the holistic nature/holism, is frequently doubtful in practice as well as in theory. CAIM practices such as the widespread use of homeopathy lack a holistic approach to diagnosis or therapy. Also, some of the theoretical underpinnings of CAIM either tend to ignore the biopathological perspective (which should be part of a holistic understanding of health), or do not go much deeper as the established bio-psycho-social model of biomedicine.
Furthermore, there can be problems especially in the case of autonomy (e.g. in obtaining informed consent). This can be traced back largely to the heterogeneity and lack of broadly established scientific and ethical/legal standards in CAIM. Thus, CAIM is not always the "best candidate" to fully conform to the ideals of medical humanism.

Dynamic informed consent in medical AI applications

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This contribution seeks to explain the impact of AI applications on informed consent and to show how AI assistance can affect physicians' considerations of the patient's best interests. Informed consent is a critical moral requirement to foster rational decision making, autonomy preservation, and the respect of individuals. Not only should patients receive relevant information, they should also understand it. The moral basis underlying informed consent can be drawn from four main ethical principles: beneficence, non-maleficence, autonomy, and justice. The concept of informed consent presumes patients are able to autonomously assess the risks and benefits to their health.

Integrating medical AI applications into decision-making processes supports physicians across many clinical procedures where turnaround is measured in seconds. Physicians are especially confident in relying on AI systems to make a medical diagnosis, prognosis of disease, or treatment recommendation, and this may entail complex interactions with AI to identify data patterns and generate assessments. Applying AI to clinical decision making or clinical practice presents, however, both benefits and ethical risks and challenges.

The impact of technological transformations is likely to affect the physician-patient relationship in terms of respect for patient autonomy, protection of personal data or medical interests, and trust. Epistemic challenges associated with the lack of transparency and explicability in the context of informed consent deserve consideration. AI systems are presently characterized as "black boxes" wherein neither the engineers nor the users of the system can fully account for or comprehend how AI reaches decisions or evaluations. Interpretation-based assessments by AI with little transparency and explicability decrease the reliability of the overall diagnostic process. Keeping in mind that the physician's understanding of how AI systems work and the epistemic mandate for believing AI assessments are correct is critical. Under opaque conditions, the physician cannot justify the judgments needed to fully inform patients about the upcoming treatment.

The shortfalls in transparency and explicability when using AI in healthcare, coupled with the need to fully inform patients, are challenges that a *Dynamic Informed Consent* attempts to overcome. It benefits both patients and physicians with a positive outcome, allowing for greater transparency, for patients' responses to be tracked across different time points, enabling in turn more frequent patient participation in clinical and research activities. Dynamic informed consent can safeguard patient autonomy, personal data, or medical interests. It promotes trust in the healthcare setting, while also being personalized and patient-centred. Moreover, it fosters interactivity, enabling patients to consent to new treatment or change their consent choices in real time as their circumstances change. Dynamic informed consent opens up future opportunities for physicians in health care, improving outcomes and reducing costs in the long run. However, dynamic informed consent warrants further consideration of its fundamental purposes, content design, and form in situations where AI is used for diagnostics or other healthcare interventions. As such, the use of dynamic informed consent can serve to strengthen the physician-patient relationship and may become an essential prerequisite for the ethical use of medical AI.

Professional and emotional care of a patient in physiotherapists' opinion[1]

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Touch, the basic tool in physiotherapist's work, has both therapeutic and psychosocial significance. For a patient, however, touch means entering their intimate space and is connected with the risk physical, psychological and emotional boundaries violation. The main values of our adopted physiotherapist-patient relationship axiological model are care, trust, sensitivity and honesty/moral integration.

The presented results were obtained while conducting a pilot study during the process of research tool creation. The tool will subsequently be utilized to do research on a random sample of Polish physiotherapists. The aim of the study will be to verify the degree of implementation of the mentioned values.

The pilot study was carried out on a sample of 149 physiotherapists, including 107 MA students who already have full professional qualifications. They completed a questionnaire containing 157 questions prepared by an interdisciplinary research team.

The presentation will include a discussion of the research results concerning physiotherapists' opinion on the value of care in the relationship with patients. The scale used in the study was made up of 50 test items subdivided into two groups of 25. The first group referred to the opinions and behaviors concerning care resulting from professional rules and respect of patient's rights. The other group was related to care connected with patient's emotions. The study subjects evaluated each item on a 6-point Likert scale. The maximum number of points to score was 250, 125 for each group. The whole scale and subscales were analyzed by means of Cronbach's α reliability test obtaining α values proving the tool to be reliable.

The mean values for all the subjects were 80,96% of the maximum number of points for the whole scale, 83,19% for the subscale of professionalism, and 78,75% for emotions.

Then, the obtained mean values were compared using Student's t-test for grouping variables which were sex, age and being a student/working as a physiotherapist. Significant statistical differences between the means were obtained for the whole scale where the higher means were obtained by students and people from the younger age group. Significant statistical differences were also found for both subscales: professionalism (M = 103,98; SD = 12,31) and emotions (M = 98,43; SD = 12,14)

The obtained results point to the high level of implementation of the value of care in physiotherapists' relationship with patients. However, emotions in the relationship with patients are not appreciated in the same way as professionalism.

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[1] This paper is the result of the research project no 2016/21/B/HS1/01824 entitled 'Physiotherapist's Ethics. Touch, Corporeality, Intimacy', which was funded by National Science Centre, Poland.

Moral distress: A more revised, comprehensive and evidence-based theory and its mechanism are required

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Moral distress (MD) is a widely researched phenomenon, especially in nursing referring to the situation by which one believes one knows an ethical dilemma is at stake and also the morally right thing to do, but institutional constraints make it impossible to pursue the desired course of action. While over the past few decades, such a definition was widely used, and MD has

received much attention in the literature, it uncovers multiple theories and additional definitions making it difficult to explore this complex phenomenon. Indeed, along with the fact that research on MD is growing exponentially in the healthcare literature, there is conceptual confusion, lack of clarity and little cohesion about the actual meaning of it and what it means to experience it. In addition, as of this date, there is no unified and agreed upon definition of MD. Given the centrality of such a concept in nursing, this seems puzzling. A conceptual clarity of MD and its practical, measurement, management and effects are, thus, highly needed clarity with regard to many issues. In addition, there is a lack of clarity between ethical conflicts, concerns, and MD. And there also exists limited research on interventions to reduce the negative consequences of MD or to overcome MD.
The presentation will discuss those matters which are lacking and will suggest a direction by which the concept of MD should be understood and applied to justify its powerful role in the ethics of healthcare professions, especially nursing care, taking into consideration important elements such as ethical dilemmas, ethical decision making, ethical judgment and moral resilience.

Personality discrimination and hiring? Is it permissible to prefer extroverts over introverts?

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Sometimes employers use personality tests in hiring or are looking for job candidates with features of certain personalities (social, outgoing, active, extrovert etc.). They thus hire, at least partly, based on personality since they use personality traits as criteria on whom to hire for a job. Is the practice of hiring based on personality morally permissible? I argue that it is not. I claim that favouring certain personality types in hiring is often unjust. I refer to this as personality discrimination. It is wrong to hire based on personality because personality traits, such as extroversion, is something on cannot change and it is something that does not affect the job performance in most jobs. Since extroverts are currently preferred in hiring, I call a change of this practice. I suggest we need different personalities at workplaces – thus companies and organizations should perhaps hire more introverts until the bias against introverts is fixed.

Mental Health Activism and the Boundaries of Illness: Interrogating the Limits of Social Recognition

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Among the wide range of human behaviours and experiences, what is a legitimate target for medical concepts and responses? In the philosophy of psychiatry, the hope had been that clarifying the concept of mental disorder would help answer this question, with the grounds of legitimacy consisting in objectively determined dysfunction. However, attempts to provide a value-free definition of disorder – as required if the aim of objectivity is to be satisfied – have not been successful. At the same time, developments in mental health advocacy and activism present a serious challenge to the very project of naturalism about the concept of disorder. This is not merely a dispute over where the boundaries can be drawn, but a rejection of the concepts in which the problem is presented. Mad Pride and Mad-positive activism (Mad activism) resist the medicalisation of madness and reject the language of 'mental disorder'. Activists reclaim

the term 'mad', reverse its negative connotations, and present madness as grounds for identity, worthy of social recognition.
Even though Mad activism transforms the debate surrounding the boundaries of illness (by showing the inadequacy of the focus on naturalism), it certainly does not resolve that debate; it generates other boundary problems whose normative nature is more explicit. One key problem concerns the coherence of the notion of Mad identity: how can madness constitute grounds for identity, given that phenomena such as delusions, passivity experiences, hallucinations, and extremes of mood, as commonly assumed, undermine identity formation in various ways? Can this be reconciled with a demand for recognition that presupposes certain capacities for identity formation? Madness, so the claim would go, cannot be grounds for identity: it lies outside the limits of the normative theory of recognition. This talk examines this claim as follows: (1) A brief discussion of the meaning of the limits of normative theory in general; (2) an examination of the claim that madness lies outside the limits of recognition, with a focus on the assumed capacities that constitute those limits, and how madness undermines those capacities; (3) an argument for various ways in which this problem can be rectified and madness be brought within the limits of recognition.

The sex binary as a perceptive act

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For a long time, medicine has defined intersexuality primarily as a medical problem, and acted upon this presumption. Normalizing sex reassignments render intersexuality invisible and can be counterproductive from the points of view of those seeking to build positive sexual identities and communities around notions of sexual diversity (Roen 2004). A number of jurisdictions, including Germany, now require the third-gender-option ‘diverse’, in addition to ‘male’ and ‘female’. This seeks to acknowledge the human rights of non-binary people who are part of our societies (Richards 2016; Hyde 2019) and poses difficult questions about gender categorization concerning among others clinical practices and ordinary language.
Departing from Judith Butler’s notion of the performativity of gender and the gender *binary* (Butler 2004), I will focus on the perspectives involved in gender acts: (i) the perspective of those who live gender diversity and form sexual identities, who are seen and touched by others, recognized or rejected, who may be the cause of irritation for others, and (ii) the perspective of those others who see them as living their diverse genders, who may be irritated by unexpected gender enactments. The perception of gender diversity (in perspective ii) therefore must also be an act: a practice of seeing. As perceptive practice it is both highly routinized and morally relevant. It needs to be discussed from an ethical point of view.
I will focus on two perceptive mechanisms that shall be questioned from the point of view of responsibility and justice in care relationships: (i) *Binary fragmentation* of personal, bodily or behavioral features. Genderqueer others are then seen as a ‘she’ who has some male features, or a ‘he’ who has some female features, or as a mixture of both female and male features. (ii) *Sexus nullus: o*mission of sex by relying on sex- and gender-neutral perceptive levels (Hoquet 2015). Both strategies work on a pre-lingual level in perception and in explicit language. While the aim of (i) is to ‘save’ a binary gender system from the irritation that originates in the phenomenon of genderdiverse embodiments and performances, the point in (ii) is to reach out for the uniqueness and infinity of the other regardless of their gender. The discussion shall open tracks for substantial interdisciplinary bioethical research (Hiort, Jürgensen, Rehmann-Sutter 2022).

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Moral reasons in favour of bioethics consultation for pharmaceutical companies

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I will explain some of the moral reasons that speak in favour of bioethics consultation for pharmaceutical companies. Since they are major actors who shape health care systems and societies in essential ways, there are good moral reasons not to spare them from critical thought and to explain them arguments and critical aspects in an accessible language. Those physicians or scientists who work for pharmaceutical companies, even if they are identifying with their companies, are not solely official functionaries. They always stay responsible citizens and are members of legal and moral communities. Bioethics consultation is one of the 'windows' through which senior employees can connect to a rationality other than the economic logic.

Informed Consent for the *All of Us* Research Program: Experiences and Challenges at National Scale

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All of Us aims to recruit participants that represent diversity of the United States populations, acknowledging that all participants need to fully understand what participation involves, including its risks and benefits. This talk will describe perspectives on ethical oversight of the *All of Us* Research Program using a single IRB model and challenges with and novel approaches needed for informed consent at scale. This talk will highlight the philosophy behind the development of the *All of Us* protocol including the approach for obtaining electronic informed consent, careful consideration of vocabulary and reading levels in the consent documents, and the design of electronic consent to improve comprehension across participants with varying levels of educational status and digital literacy. Furthermore, the speaker will discuss how the program monitors consent drop-offs and strategies used to assess how well the information is comprehended to allow for informed decision-making. The talk will summarize findings from quantitative analysis of formative assessments included in the *All of Us* consent process and from research on informational needs of prospective participants with low health literacy.

Philosophical Aspects of Biomimetics in Medicine

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Biomimetics studies principles and ideas from nature and their transferability to technology. Disciplinary applications range from engineering,[1] to architecture, to medicine. In medicine, health care technologies are among the current beneficiaries of the careful study and utilization of biomimetics, for instance in drug delivery.[2] Biomimicry—as a tool of human ingenuity is generating particular enthusiasm from biomedical scientists and engineers, which view it as an underutilized knowledge bank, with the vast potential to hasten discoveries that benefit human health. Through the use of biomimicry, humans can bypass the evolutive paths of technology and resolve problems faster by observing already existing solutions in nature. Moreover, it is possible to find better solutions since nature is a veritable "library of information" which faces problems from different angles as humans do.[3] But, as discoveries and applications proliferate, philosophical concerns have been overlooked. In particular, the assumptive good of nature and

normative values assigned to anthropological adaptations rooted in biomimicry require evaluation.

This joint-authored paper between an engineer and an ethics faculty member in a technology university will, first, introduce the concept of biomimetics and highlight philosophical concerns about the appropriation of nature, such as the naturalistic fallacy[4] and social concerns of ecofeminist ethics.[5] The paper will, second, present the use of biomimetics in medicine, arguing for the vast potential for human health based on concrete examples spanning nanotechnologies for vaccines,[6] cartilage repair,[7] and tissue engineering,[8] followed by a discussion of the need to place biomimicry within embedded ecosystems which may affect the efficacy of human design.[9] In the third part of the paper, ethical reflection on ecological values that may support or obstruct the development of biomimicry in health care technologies, including environmental sustainability,[10] biodiversity,[11] and implications of human alterations of nature (e.g., genetic engineering)[12] will be presented. The paper will conclude by arguing for a nuanced approach to biomimicry in health care. If contextual caution is taken in human applications of biomimicry, nature can be redeemed as a normative guide without encountering the problems raised by the naturalistic fallacy or ecofeminist ethics. Further utilization of biomimicry in medicine ought to be pursued as much for pure scientific knowledge as for applications in health. However, in this technological era, which must be beholden to environmental values for the sake of human survival, medicine must question not only if humans can be trusted with nature, but also if we can trust nature itself.[13]

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eHealth and Regional Inequalities

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eHealth is the use of information and communication technology for health. This includes health services like monitoring, disease prevention, and treatments, but also administrative tasks and research. A big part of the ethical discussion around this new emerging social technology focuses on challenges that arise in the relationships between patient or user, clinicians or researchers, and the technology. Ethical concerns therefore circle around issues of autonomy and decision-making, self-perception, responsibility, and value change in the domain of health care.

As eHealth becomes more and more part of national as well as international public health strategies, ethical evaluation needs to go beyond the individual viewpoint and towards an assessment which can account for societal changes on a larger scale. This becomes even more important given that many eHealth applications can easily be distributed via the internet. The way to advance the discussion on societal implications of eHealth to a public matter of interest is to assess whether eHealth applications are able to promote justice in health care, one of the big promises often mentioned by manufacturers as well as decision makers is public health policy.

Public health ethics is concerned with the justifications as well as the just distribution of benefits and burdens of public health interventions. Although public health ethics frameworks are sensitive to the distribution of benefits and burdens across populations, they only partially address the challenges posed by large scale implementation of eHealth technology. Such challenges can arise due to regional disparities forcing some people to deal with ethical challenges more than others. It seems that the unequal distribution of tradeoffs that users and patients must face represent ethical challenges that have been neglected so far in the debate. This contribution therefore argues for a new or altered approach in public health ethics that can consider the entire spectrum of moral challenges posed by eHealth applications. Is eHealth in fact able to promote justice? And if so, what are the conditions for geographical justice in the context of eHealth?

What's wrong with life-saving drug lottery?

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Just (micro) distribution of limited healthcare resources is one of the most challenging issues in biomedical ethics. Although patients' selection is unavoidable part of everyday medical practice, there is no universally accepted set of just allocation principles. At least ten principles (and combinations of them) have been used in different allocation contexts. One of them is distribution by lottery. This approach has been recently used in a controversial global managed-access programme for a gene therapy product AVXS-101 (brand name: Zolgensma) developed by the biotechnology company AveXis, owned by Novartis.

AVXS-101 is a one dose treatment for type I spinal muscular atrophy (SMA) aimed at pediatric patients less than 2 years of age. SMA is a genetic disorder characterized by a loss of motor nerve cells in the spinal cord. The disease causes progressive weakening and wasting of muscles, especially those necessary for sitting, rolling over, crawling, walking and head lifting. SMA Type 1 is the most severe type of SMA. Without treatment, symptoms appear shortly after birth and include severe muscle weakness, lack of motor development, problems

with sucking, swallowing, and breathing. It is a life-shortening condition. In the past, for majority of children with the disease life expectancy was less than two years.
At present there are two approved treatments for SMA: nusinersen (brand name: Spinraza) and abovementioned Zolgensma**.** Other treatments remain supportive. Spinraza was approved for the treatment of adults and children with SMA both in the US (in 2016) and in Europe (2017). So far, Zolgensma gained market approval only in US in May 2019. It's the world's most expensive one-dose drug with the market price of approximately 2,1 mln dollars per treatment. Under the managed-access programme, AveXis uses a lottery to offer a limited number of AVXS-101 packages at no cost to patients from countries where the drug has not yet received market approval.
The aim of this paper is to discuss the ethics of using lottery as an allocation strategy of limited healthcare resources in general, and to evaluate the ethical acceptability of the AveXis lottery-based managed access programme for Zolgensma in particular. First, drawing from literature on distributive justice in healthcare, I will present advantages and disadvantages of allocation by lottery. Next – using a (highly imperfect, but very attractive) analogy to the just war theory – I will develop two sets of criteria of the just lottery in healthcare: the first establishing *jus ad bibendum* (the right to recourse to lottery), and the second establishing *jus in bibendo* (right conduct of lottery). I will claim that *jus ad bibendum* includes, but is not limited to the following conditions: *no prior claims* (patients, who are potential beneficiaries of a healthcare resource to be allocated by the lottery, have no prior justified claims to receive it); *right intention* (the aim of lottery is not to get publicity, but rather to distribute scares resources justly); *homogeneity* (there will be no clinically relevant differences between patients participating in the lottery); *awareness* (reasonable efforts have been made by the lottery organizers to inform all potentially interested patients about the lottery). I will argue that *jus in bibendo* should seek to minimize stress, confusion, and suffering of the participating patients and their families, notably, by providing them with accurate information, obtaining their consent, protecting their privacy, and assuring transparency of the lottery. Finally, I will analyze the rules of the Zolgensma lottery against *jus ad bibendum* and *jus in bibendo* principles. I will conclude the lottery does not meet the just lottery criteria.

Normative pluralism and rationality in medicine

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Contemporary medicine is a very complex realm and according to famous surgeon – Atul Gawande – its complexity is growing. This process is strictly bounded with advancement of medical technology and progress in medical knowledge. Medical doctors are professionally obligated to keep up with these advancements and laymen can only imagine how hard work it is.
Announcement of evidence-based medicine (EBM) program at the end of 20th century today can be considered as the declaration of providing unified and clear rules for performing reliable medicine based on the best scientific evidence. As it turned out this declaration was not a promise that complexity of medicine somehow was going to disappear. EBM doctors are supposed to gain an easy access to scientifically valid medical data and procedures. Thanks to that, they are supposed to provide the best care of their patients. EBM program was so transparent that its critics called it "cookbook medicine" and argued that EBM practitioner just has to follow such-and-such procedure and that's all. But reality is quite different.
Despite of known and recommended procedures of medicine based on scientific evidence, there is widely recognized phenomenon called "unwarranted variations" in medical doctors'

performance. Without any reasonable (in terms of EBM) justification doctors are prone to act differently in similar clinical situations. It raises the question: why is that?
In my presentation I am going to argue that "unwarranted variations" come from "normative pluralism" in domain of rationality of practitioners' performance. It means that what is considered as "rational" action under some rationality model may be "irrational" under another one. I would like to present phenomenon of "normative pluralism" in medicine along with some rationality models that may be chosen by medical practitioner.

The need for an ethical framework for health data reuse and its purposes
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Reusing existing sets of individual health data is indispensable for research and policy making. Health data are, nevertheless, frequently dispersed and stored by various data sources, such as governmental, administrative and academic actors. Consequently, data remain largely unconnected and accessing, linking and reusing health data is a complex exercise to accomplish. Divergent or unclear procedures as well as technical and legal issues hamper health data reuse even further. A recurrent element in procedural assessments and legislative regulations on health data reuse is the notion of purpose. The General Data Protection Regulation states that the further processing (i.e. reuse) of personal data should not be incompatible with the purpose for which the data have been collected initially. Moreover, the processing of health data, as a special category of sensitive personal data, is prohibited other than in some exceptional situations such as for "archiving purposes in the public interest, scientific or historical research purposes or statistical purposes".
Nevertheless, a clear ethical framework for these notions of purpose is lacking. Purposes of public interest and scientific research can be easily interpreted in line with utilitarianism, in which the greatest good for the greatest number should be pursued. From this perspective, the reuse of health data is justified by the public health purpose it serves. This utilitarian approach may result in top-down structures in which, for instance, professional and expert committees decide on this justification for health data reuse. Eventually, citizens risk being treated as means to an end and public interest, scientific or statistical purposes might supersede the actual people who are behind the required data to accomplish these objectives.
However, public health policies allow for other approaches in which citizens are involved as core stakeholders in health data reuse. Recently, several European and national initiatives, with varying degrees of citizen engagement, have been launched to take citizens' perspectives more into account. These alternative approaches may reveal different concerns regarding health data reuse (e.g. regarding the concept of health data ownership) and, more fundamentally, different ethical frameworks for the interpretation of purposes of health data reuse. If citizens tend to apply divergent ethical frameworks, this could lead to ideas on health data reuse that conflict with e.g. public interest purposes in a more traditional, utilitarian interpretation. As long as different stakeholders' ethical frameworks for purposes of health data reuse remain undefined, decisions and procedures concerning health data access, sharing and linkage may remain unclear or even arbitrary. Therefore, and in line with the general demand for transparency on health data reuse, we call for a more explicit investigation of ethical frameworks and, eventually, for the elaboration of a joint framework in which all stakeholders are fully involved, and this as a prerequisite for the development of more streamlined and effective procedures for health data reuse.

Difficulties in drawing the line – A Foucaultian view on diagnosis

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Michel Foucault´s work *Madness and Civilization* opens up a genealogical view on the handling of the mad in France from the 16th to the 19th century. What is special about his work is the perspective that operates on the edge between everything that is included in a society and everybody that is excluded from it. Foucault creates an external perspective for questions of what is normal and what is ill or mad. In this way Foucault´s methodology inquires about definitions of sickness and diagnoses particularly in the field of psychiatry and psychosomatic medicine. In so doing his work addresses the self-conception of psychologists, medical doctors and health care workers.
In my presentation I will try to use Foucault´s analysis of exclusion to get a better understanding of how definitions of sickness work in the contemporary medical context and which consequences – for example for the definition of the society of the healthy – ensue. In doing so I aim to carve out risks for patients and definitions of health that can follow from medical diagnosis using a non-Foucaultian point of view. I advocate a critical Foucaultian perspective of diagnosis that can be an aid for a self-conception of medicine that can endure in societies challenged by religious and cultural diversity.

Moral diversity and the ethics of assisted dying

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In October 2019 the World Medical Association (WMA) has re-affirmed its rejection of medical acts that are intended to end patients´ life, i.e. active euthanasia and physicians´ assistance with suicide. What is often named medical assisted dying (MAID) has become a topic of intensive debate in many developed societies and has as well prompted scholarly discussion within medicine and ethics.
The WMA states that active euthanasia and physicians´ assistance with suicide are unethical and should be rejected by the profession. The question arises if staying neutral would be an option in order to bind WMA´s members. In fact, constituent members left the WMA subsequently.
To address this question first WMA´s position is to be analysed carefully. In this paper that task is elaborated looking at arguments that were presented at regional conferences on the topic in five continents. Eventually an ethical grounding of WMA´s statement is presented.
Yet, the question remains whether WMA should avoid taking a strict ethical position in case dissenting opinions are brought forward by some of its members. E.g. during the European regional meeting representatives oft the Dutch Medical Association have requested the WMA to stay neutral. Should WMA thrust aside the ethical question of MAID and refrain from expressing a position? Critics state that proclaiming a position may patronise some members on religious and cultural grounds, i.e. motives that cannot be accepted as decisive in a secular association. Hence, arguments supporting WMA´s ethical stand must be analysed again in order to check if implicit assumptions may be identified that may not be universalized.
The pivotal argument supporting WMA´s position is hazard prevention. Weighing moral obligation against the pursuit of consensus formation human rights come into play. If human rights are at stake ethics is about the *right thing to do*. Against this *consensus formation* is of secondary value. Hence, WMA´s rejection of active euthanasia and physicians´ assistance with suicide is justified.

Ethics/bioethics committees

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Ethics committees are present in national (Italian) and international horizon of social and health structures from several decades. This article aims to offer a view of integration between the traditional experience of ethics committees, particularly for clinical practice, and the growth, testified in several European countries, of the so-called "ethical space" [*espace ethique*].
In Italy, ethical committees are present everywhere as committees for clinical trials, only in some regions and in some territories, as in the experience of Veneto, Triveneto and Tuscany, health service have committees for clinical practice. Also, with reference to pandemic situation, we can see an increase of work and intervention of ethics committees for clinical practice only in the polyclinics and large cities, while in the large part of territories only the work of the committees for clinical trials has increased. Furthermore, only some functions of the committees for clinical practice are active, for example the analysis of clinical histories and cases or formative function, almost completely forgetting other functions, about documents and guidelines or about allocation of resources.
In other part of Europe, for example in France, we can find the experience of ethical space. In a recent document, *Vulnerability and care in the community welfare. The role of the ethical space for a public debate*, the Italian Nation Bioethics Committee, starting from the Italian national plan for starting and resilience after pandemic time (PNNR), introduces a link between the ethical committees for clinical practice and the ethical space, present not only in health institutions and organizations, but also in many social and professional spheres. The integration of ethics committees for clinical practice in the ethical space, with the future "community houses" and "community hospitals" provided in PNNR, would allow the use of ethics committees for clinical practice especially in health-hospitals perspective, while ethical spaces could meet all those ethical questions that are increasingly emerging in social and professional field. The ethical space would allow a greater penetration of ethical issues at the social level, also in preview of a reduction in the number of ethical committees of both clinical trials and clinical practice, which are no longer able to cover all territorial needs. Particularly, these needs for the presence of bioethics at the social and territorial level can be linked to two fundamental trends, on the one hand, at the epistemic level, the opening towards a global bioethics which also includes social dynamics, on the other hand, most evidently happened in the pandemic emergency, the integration between (a.) medical and clinical bioethics, (b.) social and "daily" bioethics, (c.) organizational and institutional bioethics in the allocation, distribution and control of resources.

Do States Have a Moral Duty to Participate in Addressing the Global Challenge of Antibiotic Resistance?

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Antibiotic resistance (ABR) is a medical phenomenon characterized by invulnerability of microbes to previously effective drugs and antibiotics (Selgelid, 2007). ABR has recently been recognized as a global health emergency and one of the biggest threats to global health. Moreover, ABR has been seen as a problem that calls for a collective response in terms of international cooperation (Smith and Coast, 2002). Additionally, one might argue that ABR is unjust or unfair state of affairs since it is a product of an unjust distribution of socially

controllable factors that affect population health (Brock, 2015), especially of worse-off populations in developing world.
Even if one accepts the unjust nature of ABR, international cooperation in tackling ABR might not be so easy to achieve. First, since not all countries are impacted equally by ABR, some – especially affluent – countries might not have a sufficiently strong incentive or motivation to join the collective endeavour. Secondly, since the "spill-over effect" and assumed causal factors at play are far from clear, many individual countries might not find themselves morally responsible and under duties to aid in this joint enterprise.
In this paper, I address the following question: "Do states have a moral duty to participate individually in addressing the global challenge of ABR?"
To answer this question, I explicate three positive arguments: (1) the self-interest argument (Wolff, 2012), (2) corrective justice argument (Ibid.), and (3) public health emergency argument (Herington et al., 2014). However, I will show that these three arguments either fail or need to be significantly modified in order to justify imposition of individual moral duties on states to participate in containing or eradicating ABR. First, the self-interest argument fails since it rests on the arbitrariness of interests and supererogatory acts: self-interest of individual states to avoid ABR might be temporary or not recognized at all. Secondly, the corrective justice argument fails to account for disproportion between unreasonably burdensome demands on states and their causal (or lack thereof) contribution to ABR. Finally, I will argue that the public health emergency argument, once adequately modified, can serve as a justification for imposing normative duties on individual states for addressing the problem of ABR. Proposed modification consists in recognizing the effectiveness of antibiotics as a 'global public good' (Smith and Coast, 2002) or as a source of 'common heritage duties' (Ossorio, 2007).

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Empowered by technology? Reflections on the changing dementia care ethos by means of monitoring and assistive technologies

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Background: Dementia care is currently undergoing a major transformation as a consequence of demographic aging and technological developments. New tracking, sensor, and assistive technologies have become readily available to monitor and support the behavior of persons with

dementia. The aim is to promote independent living, detect or predict impending issues, relieve caregiver burden, and increase the overall quality and cost-efficiency of care.
Problem/Research Question: The implementation of such new monitoring and assistive technologies in institutional care settings such as care homes requires the social acceptance of both professionals and residents. For professionals (doctors, nurses, social workers, cleaning personnel etc.), such systems might imply support in their work (e.g., better assessment of whereabouts or moods of residents), but can also threaten their (sometimes already precarious) working conditions. Therefore, it is relevant to understand how the professional ethos and self-conception are impacted by such socio-technical systems and how changes in everyday life of the working environment are perceived and morally assessed.
Methodology/Approach: We will discuss the normative concept of empowerment and how it has been presented in the mental health care literature corpus, especially by considering professional roles as well as its normative meaning for persons with dementia. Secondly, we will reflect on the particular role, technology in dementia care can and should play for realizing the normative ideals of empowerment. Thirdly, we will identify ethical problems related to a rhetoric or even misleading conception of empowerment, especially as it occurs in neoliberal health care contexts.
Future Directions: We will provide an outlook for an empirical-ethical approach how to identify more practical and context-specific challenges to empowerment with the integration of technology into dementia care.

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Why conscience based refusals to provide patient care ought not to be accommodated
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Conscience-based refusals by health care professionals to provide care to eligible patients are problematic, given the monopoly such professionals hold on the provision of such services. This talk reviews standard ethical arguments in support of conscientious refuser accommodation and finds them wanting. It discusses proposed compromise solutions involving efforts aimed at testing the genuineness and reasonability of refusals and rejects those solutions too.
A number of jurisdictions have introduced policies requiring conscientious refusers to provide effective referrals. These policies have turned out to be unworkable. They subject patients to a health care delivery lottery, which is incompatible with the fundamental values of medical professionalism. This paper sheds light on transnational efforts aimed at undermining progress made in reproductive health by means of conscientious refusal accommodation claims.
The view that the accommodation of conscientious refusers is indefensible on consequentialist ethical grounds, as well as on grounds related to medical professionalism itself, is defended.

On the moral reasons for problematizing the dominance of pregnancy-related mHealth (despite, or because of, the promise of better neonatal outcomes)
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The concept of 'pregnancy related mHealth' (PRmHealth) encompasses a vast set of pregnancy apps and wearables, of which many promise a healthier fetal development through tighter

pregnancy monitoring. In terms of beneficence, this may be considered a morally desirable development, given that parents-to-be have certain moral responsibilities to ensure the future child's wellbeing. Yet, to assess whether such admonitions on 'responsible pregnancy behavior' are proportionate, one should at least question whether the expected benefits outweigh potential burdens or other moral drawbacks that may accompany this recommended behavior. This means that input is also required on whether PRmHealth meets the expectations about improved fetal and newborn health.
As I will show during this presentation, this is particularly relevant in view of moral concerns that PRmHealth might inflate responsibilities ascribed to pregnant persons, given that 'do-it-yourself' mobile prenatal monitoring facilitates constant access to fetal (health) information. I will argue that it is morally important that parents-to-be are able to access those means that promote a healthy pregnancy and a favorable fetal development, but that this requires considerate attention for the effectiveness of those means and possible related burdens.
To do this, I first explore, from an ethical perspective, how PRmHealth applications may impact the wellbeing of pregnant persons. While many pregnant persons express a wish to receive frequent (if not constant) updates on fetal well-being, there is nonetheless diversity among these women in terms of acceptance of such burdens and limitations of personal behavior. Hence, one should take into account that such wishes and respective choices should be seen in a relational context, so that the expressed willingness to use PRmHealth tools may be influenced by a heeded obligation to meet a norm of what it means to be a responsible, hence 'good', mother(-to-be). From this, I will argue that even if pregnant individuals are personally willing to endure certain burdens, in function of their future child's health or in order to meet expectations about responsible pregnancy, there is still moral reason to be skeptical about the ethical endorsement of PRmHealth. To support this claim, it is key to recognize that at present insufficient evidence is available to show us the benefits and burdens of PRmHealth. I conclude that such input is crucial to ethically assess whether the latter are proportionate to the former, because if this is not the case, there is a moral point in saying that endorsement of PRmHealth is overdemanding, and, hence, morally askew.

Exploring Diversity in Attitudes towards Early Diagnosis and Risk Prediction: Insights from Various Stakeholders in Germany and Israel

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Background: Recent advancements in predictive medicine and biological biomarkers promise to identify persons at-risk for development of late-onset Alzheimer's disease by detecting the physiological changes at a preclinical, presymptomatic stage. Such risk information offers an opportunity to consider one's later life with a chronic disease such as dementia. Thus, it might bring about advantages, such as planning for advanced care and financial planning. However, the lack of cure and missing effective prevention strategies as well as the likely psychological burden pose challenges for the desirability of such predictive information.
Objectives: To examine how and to what extent cultural factors influence attitudes, we compared perspectives of German and Israeli stakeholders on issues related to prediction and early diagnosis of dementia. We intend to identify similarities and differences among multiple stakeholders and assess their concerns, hopes, and expectations regarding early Alzheimer's diagnosis and prediction.
Methods: Our study included 53 German and 64 Israeli participants representing three groups of stakeholders: Caregivers of people with dementia and family members of people with Mild Neurocognitive Disorder – MND (N = 58), persons with MND (Mild Cognitive Impairment –

MCI and early dementia) (N = 31) and professional stakeholders (i.e. heads of patient organizations, physicians, social workers, etc.) (N = 28). We analyzed the main topics by qualitative content analysis.
Results: Cultural diversity shapes different attitudes as our comparative analysis shows. We identified some differences among participants, such as the stress on self-determination, responsibility and strong emotional reactions including desperation and suicide. However, quite distinctively, our cross-cultural comparison identified similar themes, too, raised by multiple stakeholders. Finding similarities indicates a universal apprehension of the disease and assessment of predictive information. The various stakeholders stressed the importance of self-determination, prevention and communication strategies, treatment options, support in care and counselling. According to concerns raised, current clinical and public communication strategies address insufficiently the affected people's needs, which also led to heterogeneity among professionals in the field on how to disclose the risk assessment in the asymptomatic or MCI (Mild Cognitive Impairment) stages or a diagnosis of (early) dementia.
Conclusions: Such cross-cultural, multi-stakeholders' framework allows us to realize that diversity in attitudes is not only embedded in social and cultural contexts, but also refers to being affected (i.e. by having a direct experience of the disease as well as hopes and concerns) and being an expert in the field (i.e. by having professional perspectives mixed with duties).

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How does global climate change impact the medical community and what can be done by providers to impact this change?
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The global impact of climate change has a great impact upon the medical community. The changes in habitat for a wide gamut of pathogens, the increasing number of many chronic medical disorders (such as cardiovascular and pulmonary diseases), the rising prevalence of drought and malnutrition, and the documented increase in climate-associated catastrophes all impact the practice of medicine.
This abstract and presentation are based on reading of current leading works of climate change including in particular those of Ghosh and Wallace-Wirth and peer-reviewed medical literature.
The medical community should increasingly engage in the cataloging of climate-associated phenomena and diseases. International organizations need to catalog the variety of climate impacted diseases (e.g., Lyme disease, malaria, dengue fever, Chikungunya virus, and Zika virus). SARS-19-CoV=2 has had a not altogether negative impact on climate change in that decreased transportation and decreased use of fossil fuels has abated some climate changes.
A recognition of the values of solidarity and social utility in finding solutions for climate change is important. The bargaining impact of physicians was evident in their approach to the nuclear conflict in the 1980s with the NGO International Physicians for the Prevention of Nuclear War, and international medical organizations can form coalitions that expressly address climate change.
The needs of migrants and peoples impact preferentially by climate change needs particular attention. With whole territories and nations (the Marshall Island, Reunion, Seychelles) threatened by extinction, solutions are needed that incorporate compassionate means to address to incorporate such peoples into more established countries and to humanely address the needs of migrant at the borders. Mathematical modelers can incorporate philosophies of Wiener

which emphasize the iterative aspects of our decisions, the fact that our future is highly determined by the decisions we make today.
The ambivalent role of the military in its disproportionate and not fully tallied use of fossil fuels also need analysis. A telling example is evident in Ghosh in his seminal work, The Nutmeg's Curse, wherein he provides data that the allotted funds for climate change in response to the Paris Accords are but 1/600th that of the US military expense in the post-9/11 world.
Setting an example for society is important. By its relative wealth, heath care professionals and academicians can more readily drive electric vehicles, use solar panels, and eschew the organization which still promote the use of climate-damaging material such as plastics.
The final solutions to climate change will require an eradication of the use of fossil fuels, the support of carbon change industries, and the development of alternative modes of energy. Health care professionals can only do so much, but their support for these issues and candidates who address these issues can have a domino effect on society and help change the attitudes at the grass-roots level where permanent changes first take place.

What unique aspects has the COVID-19 pandemic presented in the realm of medical ethics?

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The COVID-19 pandemic is causing a devastating medical losses as well as economic damage. The ethical issues associated with the pandemic include the selective vulnerability of certain populations, the role of science in determining public policy, the balance of ensuring preventive measures against the consequent economic damage to society, and the role of determining how to selectively immunize high-risk populations.
This abstract is based on reading and assessing the current peer reviewed literature on SARS-CoV-2 virus and COVID-19 infection facilitated by providing periodic updates for an internal medicine textbook.
The at-risk populations for COVID-19 are both individual (age, diabetes, hypertension, interferon deficiency states) and population-based (Native Americans, Blacks, Hispanic), residential (nursing home and prison populations), and occupational (meat packing workers, health care personnel). The role of science is documented with studies establishing the efficacy of masks, of social distancing, and or hand washing. The ethical issues attendant with the conflict between prevention and economic lockdowns are a subject of controversy with many advocating that the economy cannot be re-established until after the outbreak is controlled with high levels of herd immunity while many leaders and business officials decrying such efforts as draconian and possibly totalitarian. The vaccines remain the ultimate goal with its safety only fully known after several million doses are administered, and the continued need to address the many unvaccinated among those opposed to vaccination globally and the many who cannot afford or have access to it in the developing world.
On a more complex and unanswered level, ethical issues include the selective use of ventilators or other high-cost therapeutics in areas with high incidence of disease and limited facilities, the extent to which the risk factor populations of COVID-19 patients reflect the underlying disparities of medical care in society, and the inability of current vaccines to meet the current need with alternative regimens including delays of the second dose, use of fractional doses (opposed by the pharmaceutical and scientific community who developed the vaccines), and implementation of vaccines that are cheaper and given once but possibly less efficacious (the Johnson and Johnson vaccine or less proven vaccines such as the emerging protein subunit vaccine Corbevax being employed in India) enabling more people to be protected.

The unique ethical issues attendant with the COVID-19 pandemic require an evolving and comprehensive set of guidelines. Paramount are the ethical issues associated with societal discrimination, individual autonomy, and definitions of individual and societal beneficence along with the need for continued global surveillance for, in particular, variants, such as recently the delta and omicron variants, that may be relatively resistant to vaccines and therapeutics.

An Ethics of Welcome

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This presentation will introduce an "ethics of welcome," an innovative approach to bioethics and healthcare policy. To welcome (etymologically, "will-come") someone is to affirm that their coming is in accord with the welcomer's will: It is *good* that you have come; I *want* you to be here, as you are. Welcome means that one is invited to come or, if already present, to stay in the company of someone who is glad of one's presence. The obligation of welcome advanced in this project is broad and demanding. It requires a radical openness to the presence of all others and a readiness and willingness to appreciate each person as a unique human being.

Though generally under-theorized, many likely agree that welcome is an obligation of health care professionals. This project claims that it is *the primary obligation within healthcare ethics* because without an orientation of welcome, other obligations cannot be reliably recognized or carried out well, whether we understand those responsibilities to arise from the Principlism espoused by Beauchamp and Childress—the predominant method in the United States of bioethics analysis—or from other ethical approaches that instead emphasize care, community, solidarity, or professionalism. An orientation of welcome is *prior* to the successful application of any of the common methods of bioethical analysis. All methods, to be truly successful, rely on the presence of individuals who are radically open to the presence of all others. Further, the obligation of welcome is not limited to healthcare professionals. As a basic obligation of human relationships, it is a mutual one, owed by everyone to everyone else, meaning housekeepers, security guards, administrators, and even patients have this obligation. An ethics of welcome speaks beyond the encounter of clinician and patient to practices, systems, and policies.

While the project draws on the work of diverse philosophers, theologians, and bioethics scholars (e.g., Emmanuel Levinas, Reinhold Niebuhr, Margaret Urban Walker, Nel Noddings, Thomas Ogletree), it is *a creative project*. Modeled on *A Pattern Language*, the iconic 1977 book on architecture and liveability, the project creates an architecture for an ethics of welcome. Rather than focusing on the moral argument for people or entities to be welcoming, it proceeds from and illustrates the assumption that human flourishing is dependent on welcoming people performing welcoming acts. The project addresses those who already want to be welcoming people. It aims primarily, then, not to answer the *why* but the *how*. The project responds to two kinds of questions: *action questions*—what would be the responsible, welcoming thing to do in this or that kind of situation? and *character questions*—how does one become a person who will recognize what should be done in this or that situation and to be ready—desiring, willing and able—to do it?

As with *A Pattern Language*, the project is built of patterns that describe and illustrate welcoming practices. Two of the patterns will be introduced in this presentation: *Call People by their Names*, and *Enter the Room and Stay There*. The patterns interrogate practices found in clinical encounters as well as in social norms, policies, and laws.

In addition to introducing these two patterns from the many comprising the project, the presentation will also distinguish an ethics of welcome from ethical approaches that emphasize or are on tolerance, hospitality, justice, empathy, or care.

Ethical Considerations When Governments Rely on Volunteer Organizations to Provide Medical Care to Immigrants Seeking Asylum: Albuquerque, New Mexico, USA

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In the spring of 2019, the U.S. saw more immigrants crossing the border, seeking asylum from Central and Southern America than ever before, and detention centers and temporary shelters at the border struggled to keep up with the large influx. After being temporarily detained, immigrants were bused to various cities and dropped off, without any food, shelter, medical care or transportation. Five major faith-based organizations in Albuquerque, New Mexico, provided temporary essential services until transportation needs were met and immigrants travelled to their final destinations. The New Mexico Department of Health (DOH) was in the midst of administrative staff changes at the time and unable to substantively assist these efforts until the faith-based organizations had already created a loose coalition to fill the void. Accordingly, the DOH took a more passive role, offering recommendations but largely deferring to the faith-based organizations.

A small research team conducted a study to determine whether the volunteer faith-based organizations had adequate protocols, leadership structures, and qualified volunteers in place to provide the medical services they did. The model followed was one of community based participatory research. Two of the five faith-based organizations and the DOH agreed to participate. I conducted informal interviews regarding the process and protocols each organization had adopted and utilized during the 4-5 month time they provided medical care to the large influx of immigrants. The aims of the project were to gain an understanding of the work flow and assess the capabilities of the organizations to whom care for the immigrants fell as well as to collect demographic information about the immigrants, including their medical symptoms.

According to the World Health Organization's report on the Health of Refugees and Migrants (2018) countries accepting immigrants should be "promoting the right to the enjoyment of the highest attainable standard of physical and mental health, equality and non-discrimination of refugees and migrants." The results of our study revealed medical volunteers working outside of their scope of practice and working on expired licenses and a lack of standardization of medical care and documentation within and between organizations and with government entities. "Everyone wants to do their own thing," an organization's leader explained. Although DOH tried to play a more stable role in the organizational structure of temporary assistance for the immigrants, they were unable to do so. The volunteer-based organizations wished to continue what they were already doing, which differed between organizations and between each bus load of immigrants. The lack of a chain of command was particularly concerning, as there was no one person, or one organization in charge to ensure quality care was being provided for this vulnerable population in a time of chaos.

This study provides an on-the-ground contemporaneous exploration of problems enfolding in a time of urgent need and raises important questions about justice, human rights, and appropriate medical care when governments rely on volunteer organizations to perform essential government functions of providing for and protecting vulnerable populations.

Research on ageing. 120 as 20?

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Ageing is supposed to be unidirectional and unavoidable. However, the ageing process has different pace in different organisms, and also in humans. Moreover, there are organisms that do not age. Human lifespan has significantly increased due to modern healthcare (hygiene, vaccines, antibiotics and successful surgery). However, as the years go by, chronic diseases develop. The question is whether these diseases are the reason or the result of ageing.
Current research asks what is ageing; and why it occurs. It aims at delaying the ageing process; or even reverse it. However, is this research desirable? Or welcomed?

Epistemic Injustice and Informed Consent in Psychiatry

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In medical care, informed consent is taken to be required prior to the distribution of care in order to ensure that patients fully understand the potential risks and benefits of a given medical procedure. However, some patients – for example children – are taken to lack the decisional capacity to provide legitimate consent to care. In such cases, consent is typically given by health care proxies or surrogates, who are designated to look out for the interests of what are considered to be particularly vulnerable populations. In this paper, I will consider another group that is often taken to be incapable of providing legitimate informed consent – populations with psychiatric disorders. How could informed consent operate in psychiatric populations that are particularly vulnerable?
Some may suggest that it couldn't. Many psychiatric conditions can involve acute changes in one's preferences or reasons for action that it is possible patients would not endorse afterwards. Also, at least some of the reasons offered in psychiatric contexts are not governed by the constitutive ideal of rationality, so are considered to be either bad reasons or fundamentally not reasons at all. Finally, refusal of treatment – if taken by the clinician to be unreasonable – can be grounds for claiming that the patient lacks decisional capacity to consent in the first place. Given such a background, psychiatric patients seem like prima facie bad candidates for providing legitimate informed consent.
In this paper, I will consider this question through the lens of standpoint theory. Given that psychiatric patients are members of socially marginalized groups, standpoint theory would suggest that they are socially situated in ways that give them privileged epistemic access to relevant features of their worlds relative to the non-marginalized. Epistemic standpoint enables service users to recognize the ways in which they are systemically excluded and discriminated against, which might not be obvious to those outside their social situation. As such, I will suggest that in at least some cases, denying the ability to consent constitutes an epistemic injustice toward service users. In these cases, allowing service users the ability to consent not only respects their expertise regarding their own experience, it can be a useful tool in achieving the aims of the neurodiversity movement.

Diagnosis as a moral dilemma: case of autism spectrum disorder

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My project aims at questioning the nosology of autism spectrum disorder (ASD) and studying its influence on the diagnosis of ASD by observing and analyzing the clinical reality. Indeed, the moment of the diagnosis is a key moment for the patient since it represents for her/him the origin of the disease. Moreover, the diagnosis is affected by different elements such as international classification - especially the DSM as we talk about psychiatry - medical experience and social evolutions. Autism is a very specific disorder, still largely unexplained, which covers a large spectrum of possible associated symptoms. In international nosologies, this syndrome has undergone a great number of changes and developments. Criteria for diagnosing ASD and its place in the nosology (DSM) have been changing a lot over the last few years. In its last version, published in 2013, only two criteria remain relevant: « persistent deficits in social communication and social interaction across multiple contexts » and « restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following ». These new criteria led to an « epidemic of autism » (Hacking, 2013). This shows why it is so difficult to understand autism and to what extent it relies on social representations. Nowadays, autism is a crucial societal problem and social sciences deeply need to study it.
My oral presentation will focus on the diagnostic process itself and aspires to determine the part of each element - DSM, medical experience, social representations - in the diagnosis of childhood autism. One of my main objectives is to understand if ethical considerations are at stake when professionals make the diagnostic decision. Social representations about autism are various, from the child who suffers of aphasia and stereotypies to the brilliant one, the "little genius", shown in TV series. Given these social representations and impact of the ASD diagnosis, is it still appropriate to diagnose someone at the border of the spectrum? Since the diagnosis of autism involves deliberation, it is legitimate to wonder if the impact of the category on patient's life is taken into account in the exchanges leading to the diagnosis. The study I will present relies on interviews with health professionals and observations in relevant departments. I have attended medical consultations devoted to ASD diagnosis and meetings between psychiatrists, psychologists, speech therapists, psycho-motor therapists, and social workers who are involved on a daily basis with sharing their own observations and conclusions in order establish a diagnosis. This diversity of the profession involved shows the variety of criteria that can be taken into account. In this respect, questioning diagnosis as an ethical dilemma seems necessary in the case of ASD.

Autonomy in Politics and in the Definitions of Health and Disease

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In the last 50 years thinking about both medical ethics and the definitions of health and disease themselves has given a central place to *individual autonomy*. In politics, the notion of individual autonomy functions to set up a minimal sphere of protected rights, and to prevent the state from endorsing, imposing, or punishing specific substantial conceptions of what counts as a good human life (religious or secular): such conceptions are rather understood as individually chosen. The result is a rights-based pluralism protecting fundamental individual interests while otherwise allowing the existence and co-existence of a wide array of conceptions of the good life. This pluralism gives the individual decision-maker pride of place in the determination of

what is good or bad, beneficial or harmful, for her. As such, individuals must recognize their projects, commitments, and ways of life as one amongst many in return for broad freedom to live their lives as they choose relatively unmolested by government or society.

In medicine, by contrast, particularly concerning the definitions of health and disease, we might expect the situation to be otherwise. While there might be many substantial conceptions of the good life, it is natural to think there is but one definition of health and disease, one depending very little on individual choice. Yet a major tendency in central analyses of health and disease goes in the opposite direction. Both Boorse's biostatistical account of disease (and illness) and normativist accounts, such as those of Cooper and Nordenfelt, give the individual's choices significant leeway in determining, not just whether or not they are bothered by their condition, but whether their condition should be classified as a disease at all. The existence of paroxetine means that whether shyness counts as an illness depends on whether the individual who has it determines it is bad for them. Whether an individual who is deaf has a disease/illness depends on their evaluation of their condition. Whether an individual with bodily integrity identity disorder who successfully carries out an amputation counts as diseased/ill (post-amputation) depends on their view of the resulting condition.

This tendency is at odds with the purported scientific authority of disease-discourse, and with the seriousness with which public opinion and social and political institutions treat health and disease, a seriousness that is comparatively absent in considerations of the proto-typical results of individual autonomy in society: conceptions of the good life. There arguably are, politically speaking, many equally valid conceptions of the good life for individuals to choose among, but it seems odd to think there are many, equally valid conceptions of health and disease. I argue that disease and health conditions that depend for their classification largely on the autonomous decision of the individual who has them should be afforded social and political significance commensurate with that accorded to substantive conceptions of the good life rather than with the more serious and involuntary status traditionally afforded matters of health and disease. Ideally, definitions of health and disease themselves should take this into account.

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Travelling to die: Views, attitudes and end-of-life preferences of Israelis considering receiving aid-in-dying in Switzerland

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Background: Following the increased presence of the Right-to-Die Movement, improved end-of-life options, and the political and legal status of aid-in-dying around the globe, suicide tourism has become a promising alternative for individuals who wish to end their lives. Yet, little is known about this from the perspective of those who engage in the phenomenon.
Methods: This study applied the qualitative research approach, following the grounded theory tradition. It includes 11 in-depth semi-structured interviews with Israeli members of the Swiss non-profit Dignitas who contemplated traveling to Switzerland for aid-in-dying.
Results: Seven themes emerged from the data analysis, including health and functioning; feelings regarding survivorship and existence; interacting with the health sector; attitudes regarding death and dying; suicide; choosing death; and choosing suicide tourism.
A significant portion of the participants had experienced suicidal thoughts and had even previously attempted suicide, some more than once. Most of them referred to chronic illnesses, functional disability, and social isolation. They understand suffering within the subjective dimension, namely only by the person who is actually subjected to the disease, ailments, and disability.

Participants regarded aid-in-dying in Switzerland as positive thanks to its guaranteed outcome: "beautiful death", compared to "disadvantaged dying" which places a burden on the participants' loved ones throughout the prolonged dying. Most of them do not necessarily want to have their loved ones beside them when they die, and they see no significant meaning in dying in a foreign country to which they have no emotional or civil attachment.
Conclusion: The desirable approval or tragic refusal by Dignitas to participants' requests for suicide tourism enhances the paradox between the perception of aid-in-dying as a mechanism for fulfilling controlled death and its bureaucratic and materialistic characteristics specifically reflected in a paid, formalized approach to aid-in-dying that cultivate dependency and collaboration

Experiences and attitudes of medical professionals on treatment of end-of-life patients in intensive care units in the Republic of Croatia

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Decisions about limitations of life sustaining treatments (LST) are made for end-of-life patients in intensive care units (ICUs). Studies have shown that withholding and withdrawing of treatment and shortening of the dying process were used less frequently in the southern European countries compared to the central or northern countries. It has also been shown that Catholic physicians and medical professionals are less inclined to follow a competent patient's wish to refuse a treatment that might be lifesaving. The aim of this research was to explore the professional and ethical attitudes and experiences of medical professionals on treatment of end-of-life patients in ICUs in the Republic of Croatia.
A cross-sectional study was conducted among physicians and nurses working in surgical, medical, neurological, and multidisciplinary ICUs in the total of 9 hospitals throughout Croatia using a questionnaire with closed and open type questions. Exploratory factor analysis was conducted to reduce data to a smaller set of summary variables.
Less than third of participants (29.2%) stated they were included in the decision-making process, and physicians are much more included than nurses ($p<0.001$). Sixty two percent of participants stated that the decision-making process took place between physicians. Eighteen percent of participants stated that 'do-not -attempt cardiopulmonary resuscitations' orders were frequently made in their ICUs. A decision to withdraw inotropes and antibiotics was frequently made as stated by 22.4% and 19.9% of participants, respectively. Withholding / withdrawing of LST were ethically acceptable to 64.2% of participants. Thirty seven percent of participants thought there was a significant difference between withholding and withdrawing LST from an ethical standpoint. Seventy-nine percent of participants stated that a verbal or written decision made by a capable patient should be respected. Physicians were more inclined to respect patient's wishes then nurses with high school education ($p=0.038$). Nurses were more included in the decision-making process in neurological than in surgical, medical, or multidisciplinary ICUs ($p< 0.001$, $p=0.005$, $p=0.023$ respectively). Male participants in comparison to female ($p=0.002$), and physicians in comparison to nurses with high school and college education ($p<0.001$) displayed more liberal attitudes about LST limitation.
In conclusion, DNACPR orders are not commonly made in Croatian ICUs, even though limitations of LST were found ethically acceptable by most of the participants. Attitudes of paternalistic and conservative nature were expected considering Croatia's geographical location in Southern Europe.

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Human genome editing: between universalism and particularism

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In the field of bioethics attempts to find the balance between universalism and particularism are still made. On the one hand, universalist approach based on the assumption that normative role of bioethics is crucial as well as establishing applicable universal principles, especially considering the ongoing process of globalization of bioethics. This approach leads to the conclusion that taking into account moral, religious and cultural diversity results in ethical relativism and as a outcome generates fallacious and unjust solutions in medicine and healthcare. On the other hand, the fundamental principle of bioethics is to ensure respect for cultural diversity and pluralism. Particularly in the area of bioethics it is difficult to postulate that established solutions – abstract standards – should be always applied in individual cases regardless of social and cultural differences. Some opponents of universalism even recognize that *respect for diversity is an ethical imperative and the most appropriate way forward for "global bioethics"*. The problem of tension between universalism and particularism is especially significant in the face of the most contentious and disputed bioethical issue, such as human genome editing. Studies involving editing of the human genome raise a lot of controversy. In this debate, the only common ground seems to be that the limits of acceptable interventions in the human genome should be clearly defined. The problem of how we should determine them, whether such a decision should be left to the authority of scientists, patients, governments or whether we need new regulations in this area at all, remains a matter of discussion. An additional issue is how to enforce on the scientific community regulations and restrictions in researches involving the editing of the human genome. This study will be focused on challenges posed by research in the area of human genome editing from the perspective of two indicated approaches: universalism and particularism.

EU Research Project „Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe"

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Healthcare, understood as a medical space, is an excellent example of a public space that models the processes of social integration and social equity. Healthcare can connect diverse groups of a society under the common idea of health and illness. However, depending on its organization, it can also influence societal segregation of minority groups.
Although the issues of minorities' equality are central to the European Union, the Member States of the European Union retain general powers regarding regulations of the status and the position of minorities on their territories. In doing so, they should respect the rights of the minorities and promote equality in accordance with European Union's regulations. In the focus of this EU research project stands analysis of European norms and guidelines concerning social diversity and access to healthcare as well as their implementation in national normative frameworks and healthcare practice in a comparative perspective of four European countries: Croatia, Germany, Poland, and Slovenia. The research focuses on the concept of diversity that includes aspects of ethnicity, religion, gender, and sexual orientation in the context of ethical, cultural, and normative aspects of integration and exclusion within the healthcare sector.

The presentation addresses the concept, methodology of the project and demonstrates the up-to-date results concerning the issue of equal access to healthcare in an international perspective of the European normative framework.

Bioethics Engagement with Industry: A Reality Test with Consequences
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Bioethics engagement with industry provides an opportunity to help prospectively identify potential ethical challenges associated with emerging biotechnologies and sometimes help to mitigate them in practice. Thus, such engagement can help avert adverse consequences, both social and corporate. In addition, informed by stakeholders grappling with actual problems, much like clinical ethics, this practical bioethics work can test standard assumptions and approaches, thereby providing means to enrich them. Nevertheless, it is essential to structure bioethics engagement with industry in such a way that it can be done with integrity. In this talk, I will discuss some of the ways it can be possible to do responsible bioethics engagement with industry.

Strengthening Global Human Research Protection Programs
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In this presentation, faculty will address current global bioethical trends focusing on research practice and policy, and, in particular, the goal of providing robust protections for the safety and welfare of human research participants, through the development and maintenance of strong Human Research Protection Programs (HRPPs). One model for ensuring quality in HRPPs is through accreditation, and the worldwide leader in HRPP accreditation is The Association for the Accreditation of Human Research Protection Programs, Inc. (AAHRPP). AAHRPP is a global non-profit organization that promotes high-quality research through an accreditation process that helps organizations strengthen their human research protection programs (HRPPs). This presentation will describe universal features to strive for in the development of a strong system of protections and will, correspondingly, highlight how AAHRPP accreditation can play an important role in building that ethical foundation.
By way of background, as an independent, non-profit accrediting body, AAHRPP uses a voluntary, peer-driven, educational model to ensure that HRPPs meet rigorous standards for quality and protection. To earn accreditation, organizations must provide tangible evidence—through policies, procedures, and practices—of their commitment to scientifically and ethically sound research and to continuous improvement. As the "gold seal," AAHRPP accreditation offers assurances – to research participants, researchers, sponsors, government regulators, and the general public—that an HRPP is focused first and foremost on excellence. AAHRPP, through accredited research programs worldwide, works to help ensure that all human research participants are respected and are protected from unnecessary harm. AAHRPP includes and partners with organizations and research participants and their communities to encourage best practices and set effective, reasonable standards that add value to human research protection programs around the world.
As with most accreditation programs, AAHRPP accreditation uses a set of objective Standards to evaluate the quality and level of protection that an Organization provides research participants. Through accreditation, an Organization can demonstrate the overall excellence of

its research program by providing the most comprehensive protections for research participants. An intensive self-assessment is the first and most important step in the process that results in continuous improvement. Following that, a site visit conducted by colleagues from like organizations provides another layer of evaluation and education.
Accreditation benefits research participants and organizations in many ways. Each time a new Organization becomes accredited, the global benchmark for human research protection in science is raised.
The primary purpose of AAHRPP accreditation is to strengthen protections for research participants. Each accreditation advances that objective and helps build public trust and confidence in research.

The conceptual shift from altruism to reciprocity is needed for ethical justification of kidney exchange programs

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The basic ethical principle on which organ procurement has been set up is altruism. However, this principle has been challenged by chronic inability of altruistic organ donation to copy with the demand for transplant organs for several years. The disproportion between organ supply and demand, especially for kidney transplantations, continues to widen with years.
The most important innovations in the policy of organ procurement in the last two decades has been the kidney paired exchange (or kidney paired donation) and its expanded variations called the domino kidney paired donation, and recently the global kidney exchange. The idea of kidney paired exchange is very simple - when directed living donor is unable to donate to their emotionally related recipient due to an immunological incompatibility, they can overcome this biological obstacle and exchange the kidney with another such pair. However, opponents of the kidney exchange scheme see it as a quasi-contractual arrangement and as a step toward for-profit transactions, and therefore as a policy which undermines the organ donor system grounded on altruism. This critical attitude has not changed after recent legalisation of kidney exchange in the USA. In fact the legalization of kidney exchange has been now used as an argument for supporting kidney market proposals, since kidney exchange, as they argue, is a barter, which is a fundamental form of market. This of course is supporting those who claim that kidney exchange is a step towards legalizing of organ market and therefore it is immoral.
I focus on the ethical analysis of kidney exchange transplant programs, including the most controversial form of global kidney exchange. I argue that kidney exchange model is not possible ethically justify within the altruism paradigm, but it is possible to do it with the reciprocity approach and at the same time not to allow organ commodification.

Relational autonomy in the light of hope in end-of-life care

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The paper examines the concept of *relational autonomy* elaborated by Mackenzie and Stoljar (Mackenzie and Stoljar 2000) and developed by Walker and Lovat, Gómez-Vírseda, Maeseneer, Gastmans (Walker and Lovat 2015, Gómez-Vírseda et al. 2020). Within this framework, autonomy is based on relationships, in which the agent's decisions are made in conjunction with others, e.g., the agent's caregivers. In the paper the concept of *relational autonomy* will be further developed in the context of palliative care philosophy where one's

spiritual, psychological, physical, and social needs are an indispensable part of medical treatment and in the context of different experiences of hope as being focused on quality of life of patients and their caregivers rather than on a cure. One of the most important issues when it comes to palliative care is not only how this care should be carried out but also when, where and *with whom*. In some cases, when making decisions we must be aware of the risk of that harming someone for the sake of higher needs (e.g. the need to maintain a patient's hope at the cost of carefully choosing the right moment when to inform the patient about potentially harmful circumstances) because hope can be taken away with a few (sometimes careless) words. Additionally, following the Hippocratic principle of medicine 'first, do no harm', it is worth nothing that this principle should be understand in the context of *relational autonomy* as well as in the perspective of palliative patients and their caregivers with special regard to spiritual and religious experience of palliative patients, the needs of family members who are taking care of their relatives, the experience of healthcare from patients and caregivers perspectives (communication issues, personal and social support), the role of hope in palliative care, moral dilemmas such as: caregivers' difficulties of meeting patients' sadness over the injustices about not being healthy and being close to death, existential dilemmas when caring for a person over a long period of time without being aware of the person's wishes, dilemma about withholding information (diagnosis), informing the family or hiding information according to patients' wishes, caregivers' dilemma of not taking away patients' hope or to inspire too much hope when this is not realistic etc.
On the one hand, from the perspective of health care professionals the most important aspect of medical care is to ensure a proper diagnosis as a basis for further treatment. On the other hand, any unnecessary harm should be avoided in therapeutic relationships so that the patients and their close ones can focus on handling the diagnosis and concentrating all their efforts on planning care.

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A bioethical policy debate concerning the recent 'surrogate mother' case in Russia

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After the death of an infant in early 2020, children born by surrogate mothers and waiting to be sent abroad to their adoptive parents were found in an apartment in Moscow. Initially, investigators were unable to find a genetic link to the parents-customers, so it was assumed that the biomaterial had been donated by ordinary Russian couples whose surplus embryos were transferred to surrogate mothers. The newborn babies were then handed over to foreigners. The physicians involved and a number of others were subsequently charged with human trafficking, which carries a sentence of up to 15 years in prison. Despite the fact that the ordering father later confirmed his genetic connection to the babies, the investigation is still ongoing.
Commercial surrogacy is allowed in Russia, but various aspects of contracts for transferring a child to genetic parents are not regulated. Moreover, the issue of medical tourism, in which prospective parents from other countries come to Russia to hire a woman to carry and give birth to their child, is also not regulated.

The "surrogate mother" case has stirred up all of Russian society. However, instead of a full-blown bioethical analysis with normative provisions regarding ethically acceptable guidelines and rationale for surrogacy, it was first proposed to prohibit the procedure in private clinics and then to ban commercial surrogacy for foreigners only. This law is currently being discussed in the lower house of the Russian parliament (the State Duma). The proposed solution states on the one hand that commercial surrogacy is permissible and on the other that it is prohibited for foreigners. This prohibition is justified by the impossibility to trace and control the destiny of children exported abroad. Nevertheless, lawmakers have not taken into account the genetic link between the newborn child and the ordering parent. The prevalent thinking is that the woman who gives birth is the true parent, not the genetic parent.
Thus, instead of an in-depth analysis of the ethical situation among national and local bioethics committees and a discussion of the issues with Russian society, an administrative solution is proposed, in which an ambivalent position towards commercial surrogacy could entail a double standard, which reflects a weak mechanism for responding to emerging bioethical issues in Russia.

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Power and ethics in qualitative health (promotion) research

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A participatory health research (PHR) project was recently (2017-2020) carried out in an area in Malmö in the south of Sweden. The area in question is considered vulnerable, in the sense that it is an area with relative poverty, high unemployment, poor skills in Swedish, and reduced health expectancy, and the aim of the project was to achieve increased health equity. The project was participatory in that the community members themselves decided what their (health) problems were, and what to do about them. Six workshops (so-called living labs) on different themes, namely, women's health, mental health, oral health, social health, a safe environment, and "fitness justice," were created by the participants in conjunction with other stakeholders, including the researchers, and were led by local health promoters (who were educated for the task), sometimes together with other professionals. Research was then conducted on these activities, partly together with the participants.
Participatory health research (PHR) is part of a broader methodological field, that of participatory action research (PAR). Proponents of participatory methods make at least two claims. One of them is that results are improved and more valid when the subjects of research are actively involved in the research. The other is that the methodology is more ethically sound than other research methods, since it involves the participants in decisions at the various stages of research. Thus, using participatory methods, and thereby involving citizens in the research on themselves, can be seen as part of the democratization of (health) research.
One of the major critiques of research with humans in general, including health research, is that power is (necessarily?) exercised over the research subjects, and that this is a negative thing and perhaps unethical. The requirement of obtaining informed consent is thought to reduce the risk of unethical research. But proponents of participatory research obviously do not think that this procedure is enough, arguing that participants are left passive and have no say in what is being researched, and how it is researched. This is especially salient when it comes to "vulnerable" groups or communities.
The aim of this presentation is to examine 1) if and to what extent power might be exercised in qualitative (health) research, 2) if power *is* exercised, to what extent this is morally problematic,

and, finally, 3) in case power is exercised in a way that can be considered morally problematic, to what extent participatory research methods, as exemplified by the one used in Malmö, can wholly or partly eliminate such problems.

Participant Recruitment and Engagement - Fostering Inclusivity and Diversity in the *All of Us* Research Program

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All of Us is developing a scientific research resource that represents the socioeconomic and demographic diversity of the United States population with a focus on increased representation of people historically underrepresented in biomedical research. This approach presents new challenges and opportunities for meaningful and sustained community engagement, which is needed to build trust, set expectations, and prevent harm to participants and communities in precision medicine research. This talk will highlight *All of Us* approaches and experiences with participant engagement and feedback, and the integration of participant ambassadors in its governance bodies. The talk will also address *All of Us* strategies for facilitating trusting relationships with diverse participant populations; ensuring appropriate communication of population-specific risks/benefits, implications, and limitations in consent and other materials; and approaching bidirectional data sharing in responsible, culturally competent ways.

Obesity and its hidden tragedy of commons

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As the rates of obesity are deteriorating public health at an alarming rate much of the discussion has concentrated on issues around personal, governmental or corporate social responsibility. To contribute to the discussion, I focus on a different approach, by analysing the problem of misplaced incentives. Based on Garret Hardin's interpretation of the "tragedy of commons", I will understand the total amount of people to be fed as a population wide "carrying capacity" that is being overloaded by food processors and retailers aiming to maximize profits at the costs of public health. When food retailers and producers have "unconstrained access" to the consumers capacity to absorb food we can observe a similar effect in the deterioration of a good (i.e. adequately nourished population) as with other common-pool resources. Through this analogy I show that one of the major factors affecting the obesity epidemic is caused by the failure to internalize negative externalities (i.e. the public health costs of obesity) by the food industry while making abundant profits. This approach provides strong arguments in favour of food regulations to address public health needs inspired by the literature on environmental protection. As a conclusion, I will assess how such arguments stand against traditional criticisms against governmental regulation in the food industry.

Engaging uninformed or misinformed publics: Hearing every voice

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Sciensano, the Belgian Public Health Research Institute, organized the DNA debate, where 4,545 citizens came together to deliberate online about how we should use genomic information

in our society. The debate was set up so that citizens would first be confronted with some informational materials (an interactive test, a short video, an informational booklet or a pedagogical dossier) to educate them about the topic and then given the opportunity to share ideas. However, the citizens' responses indicate that some preconceptions and misconceptions cannot be changed in one informative action. Additionally, several citizens' ideas contained logical or linguistic errors. This means that some ideas that were shared on the platform, were based on factually wrong assumptions. For example:

- I don't want anyone to have access to my DNA. I don't want my life to be influenced by my DNA. I don't want to know that I will die October 6th 2069. [idea nr. 270]
- Since only medically schooled people can make sense of your DNA, there cannot be any misuse of genomic information. [idea nr. 351]
- Creating a genomic passport like this will limit our freedom considerably. It allows the government to track exactly where anyone has been. [idea nr. 361]
- [I don't want to share my genomic data] because they can find almost anything in there, like if you had sex recently. I mean, I don't mind to share, but I wonder what someone would do with it, why they care. But from DNA testing you can really know everything, like when you were raped and you want nobody to know but they find it in your DNA? [idea nr. 1031]

The goal of the DNA debate was to formulate recommendations for a legal, ethical and societal framework for the use of genomic technologies based on citizens' values and principles. At face value, these factually incorrect statements could be dismissed as being ill-informed. However, while these statements are all false in one way or another, they all still contain information about ethical values and principles supported by citizens. In this presentation, we will present (a) normative arguments why these values and principles should be included in recommendations following a public consultation and (b) a methodological approach of how to accomplish this, without basing policy on false beliefs. One could argue that the message these ideas want to convey is based on falsehoods or obscured by fallacies, so it would be paternalistic to interpret them beyond their original formulation. However, even the most eloquent contributions require interpretation. Thus, it is important to make use of a well-established qualitative research method to ensure a rigorous analytic process.

Every citizen will be affected by the evolution in genomic technologies. Ignoring certain ideas when trying to co-construct an ethical framework will lead to a misrepresentation of societal values and an unnecessary divide in the valuation of moral intuitions. Therefore, it is important to carefully separate flawed beliefs from legitimate concerns and incorporate the latter when constructing the final recommendations from a public engagement initiative for policy makers.

Is There a Moral Imperative to Pursue Ethnic/Cultural Diversity Among American Health Care Ethicists and Academic Ethicists?

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This presentation will argue that there is a moral imperative for ethicists working in educational settings, those who operate residency programs, and the American Society of Bioethics and Humanities (ASBH) as our national professional organization, to seek ways to actively increase the diversity of those serving as health care ethicists and academic ethics scholars, to better serve the anticipated demographic in the United States. The demographics of the United States (U.S.) have changed significantly since the birth of bioethics. Research indicates that the U.S. was comprised of over 80 percent Caucasians in the mid to late 1960s. Recent demographic trends reveal that in 2018 those who self-identified as White were 60 percent of the total population. Trend watchers have shown that several counties in the U.S. have already dipped

below 50% Whites with this trend projected to continue well into the middle of this century. ASBH has spent the past decade or more working to establish minimal professional standards among those who serve as ethics consultants. ASBH has established a formal process for certification in health care ethics consultation to ensure that those providing ethics consultation have a baseline of knowledge from which to operate. Despite some criticism, the intention of this effort is generally regarded by members as laudable. ASBH holds that the ability to assess social and interpersonal dynamics present in ethics consultation is a key assessment and analysis skill (Core Comps ASBH, page 22). This includes cultural competence. However, merely testing a candidate's knowledge of cultural competency may be insufficient to effectively serve the rapidly changing demographic of patients. Currently, ASBH does not collect demographic information on its membership, making it impossible to know the constituency of members and thus the demographic makeup of those serving in various capacities in the field. Per ASBH, there have been discussions at a Board level on the possibility of capturing this data. When this ethicist/researcher attends the ASBH conference, attendees appear to be primarily older white males, with a growing, but still minority, number of white females and an even smaller group of ethnic minority ethicists/scholars. Although observational data is the only data available presently, it does not appear that membership accurately reflects those served. Moreover, criticism exists that the cost of ASBH membership and conference attendance is prohibitive and may unintentionally reduce the opportunity for diversity. If this is the case, diversity gaps between ASBH membership and the community being served will likely widen. Given the importance ASBH places on cultural competence as a core competency and in light of the changing demographic across the U.S., there is a moral imperative to work towards greater diversity amongst practitioners. The fact that it is unlikely that ASBH membership will ever precisely mirror those being served does not diminish this imperative. Targeted improvement efforts may drive diversity among future scholars/practitioners. HEC-C is established; perhaps it is time to focus on diversity among ASBH professionals to better meet the moral and professional challenges of the changing U.S. demographic.

The Ethical Challenges of Governing Biobanking for Genetic Research in India

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Background: The promise of biobanking and genetic research (BGR) in the context of translational research towards improving public health and personalised medicine has been recognised in India. Worldwide experience has shown that incorporating stakeholders' expectations and values into the governance of BGR is essential to address ethical aspects of BGR. This paper draws on engagement with various stakeholders in the South Indian city of Bengaluru to understand how incorporating people's values and beliefs can inform policy making decisions and strengthen BGR governance within India.
Methods: We adopted a qualitative research approach and conducted six focus group discussions with civil society members and seven in-depth interviews with key informants in BGR, identified through a targeted web search and snowballing methods, till data saturation was reached. Data were thematically analysed to identify emergent patterns.
Results: Specific themes relating to the ethics and governance of BGR emerged. Fears on the uncertainty about future sample and data use, possibilities of discrimination and exploitation in the use of findings and the lack of comprehensive data protection policies in India along with expectations of enhanced contributor agency, control in future use of samples and data, benefit sharing, enhanced utility of samples, sustained BGR and public good, reflected tensions between different stakeholders' values and beliefs. Fair governance processes through an

independent governance committee for biobanks and a system of ongoing engagement with stakeholders emerged as best practice towards building trust and respecting diversity of views and values.
Conclusions: Ensuring public trust in BGR requires listening to stakeholders' voices, being open to counter narratives and a commitment to long term engagement embedded in principles of participatory democracy. This is central to a 'people-centred governance framework' involving a negotiated middle ground and an equilibrium of governance which promotes social justice by being inclusive, transparent, equitable, and trustworthy.

Professional expertise in giving ethical advice. Empirical data and ethical analysis from clinical ethics consultation in psychiatry
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Background: Clinical ethics support services (CESS) are increasingly advocated in psychiatry. An important challenge to further development is to improve their ability to react to the moral needs of professionals by providing a professional ethical expertise. However, concepts of expertise as well as definitions of scope and responsibilities of CESS are often manifold and vague.
Objectives: To explore concepts of ethical expertise in CESS in mental healthcare and to analyze challenges in providing ethical advice in different types of ethical problems.
Methods: Qualitative study with mental healthcare professionals and ethics consultants triangulated with non-participant observation of decision making of CESS. Analysis according to grounded theory.
Findings: Analysis of 12 Interviews and 4 observations shows CESS-members to perceive a double bind dilemma as ethical experts. As ethically trained persons, CESS-members reject the idea that their judgments have expert-status. However, they feel that professionals reach out for guidance and that it is their responsibility to offer it. Furthermore, data reveals different dimensions of ethical problems professionals want to refer to CESS: treatment-, inter-patient- and systematic conflicts between different parts of healthcare system. However, CESS-members focus on the first two dimensions while the third remains unnoticed.
Conclusion: Double bind dilemma leads to insecurity of experts regarding their professional role. Conceptual clarification and implementation in training is needed. Unregarded types of problems lead to risks of frustration and may affect satisfaction. Different strategies to overcome this challenge need to be discussed: either to restrict scope or to adapt concepts of problem-solving to practitioners' needs.

Frailty as a priority setting criterion for potentially life-saving treatment – self-fulfilling prophecy, circularity, and indirect discrimination?
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Introduction: The National Institute for Health and Care Excellence (NICE) in the UK developed guidelines that use 'frailty' as one of the priority-setting criteria for how scarce, but potentially lifesaving, healthcare resources should be allocated during the Covid-19 pandemic. Frailty was also used in many other guidelines We discuss the ethical implications and argue that this is an unproven and ethically problematic form of healthcare rationing.

Methods: CINAHL, Embase, MEDLINE, and The Philosopher's Index, were searched from their inceptions until December 2020 for papers relevant to the ethical or gerontological debate surrounding the use of frailty as a priority setting criterion for potentially life-saving treatment in an acute setting.
Outcome: Twenty-seven papers were included in this review. Only one of our included papers was published before January 2020, with the remaining 26 included papers published after January 2020. Frailty as a priority setting criterion was inspired by the Covid-19 pandemic.
Conclusions: It appears that the global medical community was ill-prepared to ration acute treatment in a pandemic setting and that global frailty scoring rose to the top as the most palatable and seemingly most legally acceptable rationing tool. We show that using global frailty scores as a criterion for access to acute treatment is methodologically and ethically problematic. The term 'triage' has been used to defend the use of frailty as a criterion to deny the frail treatment, however, we conclude that using frailty as a criterion to deny patients treatment is denying them something valuable on a potentially discriminatory basis.

Single mother by choice – a contested account of parenthood

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Currently, a reform of the embryo protection law is being debated in Germany. In comparison to other European countries the German regulations on reproductive medicine are restrictive. They are considered outdated with regard to the rapid social change that is also taking place in terms of family and parenthood models (Eggen 2020, Kuhnt and Passet-Wittig 2022). Sociodemographic change, altering lifestyles, and rising infertility predict an increase in medically assisted reproduction technologies (MAR). The increase in MAR has the potential to decouple sexuality from procreation and thus evoke different models of parenthood. However, the regulations for implementing assisted reproduction are not adapted to social reality. Rather, the use of MAR is subject to strong social selectivity. Health insurance support and medical ethical guidelines reproduce the ideal of the married and thus biological parent couple by continuing to make access to MAR more difficult for alternative life concepts (Köppen, Trappe and Schmitt 2021).
In this talk, I would like to explore a concept of parenthood that in no way corresponds to this ideal: motherhood as a single woman. Singles and same-sex couples are among the social groups with the greatest obstacles to the use of MAR (Köppen, Trappe and Schmitt 2021). Many women affected by infertility desire to have a child without seeking a partnership or marriage (Volgsten and Schmidt 2021). However, in terms of MAR utilization, there are major ethical concerns about the concept of the single mother by choice. This talk examines the reservations about that family concept to analyze its context and to open it for discussion, proceeding in three steps:
1) In this presentation, using the German Ethics Council's recommendations on embryo donation (2016) as an example, it is shown, firstly, what reservations prevail about single mothers. The Ethics Council recommends excluding single women as recipients for donation. The focus is on concern for the welfare of the future child.
2) Secondly, it is outlined from a feminist perspective how the rejection of embryo donation for single women fits into a genealogy of paternalistic patterns that women face in the context of reproductive rights. Examples from research ethics and philosophical debate on abortion illustrate common arguments in this regard (Costantine, Landon and Saade 2020, Mayans and Vaca 2018)

3) Finally, it is analyzed to what extent a defense of the concept of the single mother by choice proclaims a more equitable access to MAR and what socio-political implications this necessarily entails. A societal recognition of the concept of single mother by choice using MAR could entail a valorization of the nearly 20% of single mothers already living in Germany (Bundesministerium für Familie 2021), thus enlivening the debate about deficits in care work from an unexpected perspective.

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Self-tracking and personalisation in healthcare

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In this presentation, I will discuss the use of self-tracking tools in medical contexts and outline ethical concerns that need to be addressed in order to employ these tools in a way that would primarily benefit the patients and not other involved parties.

Recent years have seen great developments and an increase in popularity of various self-tracking technologies. These include consumer devices like smartwatches and fitness bands used to collect data on everyday activity, as well as more specialised tools such as blood pressure trackers or continuous glucose monitoring sensors. These self-tracking technologies have been adopted by patients and physicians as they facilitate the collection of data useful in addressing numerous conditions. Even though self-performed measurements cannot be a substitute for specialised tests and regular in-person consultations, self-tracking technologies enable the collection of medical data that would be too impractical, expensive or even impossible to be gathered in standard medical environments. Moreover, since self-tracking patients do not need the help of trained staff, they could monitor their bodily measures over a greater period of time.

Consequently, self-tracking devices are enthusiastically marketed and discussed as technologies that could facilitate the move to a more patient-oriented medicine. Their relatively low cost and ease of use make it feasible to offer patients personalised healthcare solutions independent of standardised procedures and rigid institutional structures. And while self-tracking medical devices could make it easier to attend to the diverse medical needs, overreliance on them might lead to two crucial problems.
First, they could burden the patients with excessive responsibility over their health. To be healthy or recover from illness in the age of self-tracking devices, one needs not only to regularly visit the doctor, take their medicine and live a healthy lifestyle, but also to constantly monitor and optimize countless parameters pertaining to their bodily processes. Failure to do so could be seen as irresponsible, or even jeopardizing own health. Additionally, since with the development of self-tracking more and more specialised measurements can be done by patients, healthcare providers could be incentivised to offload to the patients some of the monitoring that was previously within their responsibility.
Secondly, with the limited possibility of regular consultations with trained professionals (especially if the discussed devices are used and prescribed as a cost-cutting measure), the users have to make sense of the collected data on their own or with the help of models created by the developers. While the former leads to obvious issues related to patients' lack of practical knowledge, I will argue that the latter is more problematic as the ideas of the body promoted by the developers of self-tracking tools rarely take into account the diversity of their users and promote the ideas of the body and standards of excellence that can often be met only by a small fraction of people (usually those who are young, white, male and relatively wealthy).

How to design consent for research in democratic societies? An analysis of arguments of solidarity

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In the context of medical ethics, solidarity is often employed to counter arguments based on what is by many perceived as too narrow an idea of individual autonomy. In the debate about appropriate consent for biobank and data-based research, for example, solidarity has been referenced to argue against too strict demands of study specific consent.
Pluralistic democratic societies cannot ignore the demands of autonomy and rights to self-determination, but contrasting these with considerations of solidarity seems at first glance a promising approach. Democracy is not, after all, limited to supporting the pursuit of self-interested goals, but also meant to further transparent debates about shared goals and values. It should allow for people showing solidarity with each other, especially in cases where this is aimed at the support of disadvantaged minorities. A closer look at how solidarity is employed in bioethical debates, however, reveals different and often confused conceptions of solidarity.
In this talk, I will analyse arguments related to solidarity on the basis of three different conceptions of the term: Solidarity will be considered as an individual motivation, as a social practice, as well as a conception of morally required mutual support in a society.
I will argue that a conception of solidarity as individual motivation can indeed offer a convincing argument against too narrow an understanding of individual autonomy. It reminds us that people often have a genuine interest to help and support others and that respecting their right to self-determination also means to allow for the realization of such interests.
A conception of solidarity as referring to social practices of mutual support is usually taken to be a normative conception. Solidarity is here understood as a practice with some prima facie value. But the overall value of such a practice still needs to be determined in reference to its

goals. The ‘dark side’ of solidarity, its potential for exclusion of already disadvantaged groups, needs to be considered here as well as in the first conception. A just society has no interest in furthering every kind of solidarity.
In the context of consent debates, both conceptions can be employed to argue for broader and more tailored consent options to allow individuals to express solidarity. The scope of such arguments, however, is limited as they also allow for the exclusion of and discrimination against disadvantaged groups.
Only a third conception of solidarity, one that limits the use of the term to contexts where acts of support are morally required (usually in reference to reasons of equity) escapes this problem. Such a conception of solidarity, I will argue, stands in favour of a model of broad consent where other safeguards to protect individual interests are in place. As this conception, however, refers to moral duty rather than to individual choice, it still needs to be weighed against considerations of autonomy.

Diversity of men who have sex with men (MSM) as ethical problem and potential in new strategies of HIV prophylaxis
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Given that condoms provide ample protection against both HIV as well as other sexually transmitted infections (STIs) and given that safe access to HIV post-exposure prophylaxis (PEP) also exists (relied upon after condom fatigue, for example), it should be thoroughly investigated if and when the increasingly popular HIV pre-exposure prophylaxis drug (PrEP) presents itself as the superior alternative. In the area of conflict between medicalization, in particular of men who have sex with men (MSM), and highly potent HIV prevention methods, it should be determined when exactly PrEP (either via daily dosing or on-demand dosing) trumps the use of condoms or PEP. It should be noted that this medical-ethical inquiry deals with the diverse group of MSM whose individual sexual behavior requires especially individualized HIV prevention strategies. In the context of a generalized *everyone at risk* approach towards MSM, PrEP is becoming increasingly established as a standard of care. There is no doubt that this is desirable for certain MSM with a particular risk profile; however, variance in MSM (e.g. engaging in casual condomless sex versus random condomless sex) must be assumed and taken into account in order to avoid disproportionate medicalization. This study argues for highly personalized decision-making in the possible indication for PrEP among MSM. The methodology of this work is based on an evaluation of the interdisciplinary literature on PrEP in particular and on HIV prevention in general. Both topics focus on the current status of clinical research and on the medical-ethical debate. The medical history of prevention and of HIV proves relevant for the largely ongoing ethical study of PrEP usage and provides the following methodological framework: firstly, both the obvious subject areas are presented – PrEP as a *new wave* in HIV prevention in MSM (part I) and the current medical-ethical discussions on this (part II). The medical-ethical argumentation is rooted in a discourse between PrEP’s specialist prevention strategy and the history of ill-health prevention and disease prophylaxis (part III). Important findings from this comparison shall then be applied to the medical-ethical analysis of PrEP (part IV).

Diversity in the ethics committee for the protection of animals used for scientific purposes
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The question of animal use in science brings a lot of emotions, whether discussion takes place in media, or in Academia. Under the EU law animals can only be used for a limited number of research purposes and every research project that makes use of animals must be authorised before it starts. A project proposal is evaluated through a harm-benefit analysis by the 'competent authority' in each EU Member State, which then decides whether to grant the license or not.
Every EU country has a national ethics committee for the protection of animals used for scientific purposes. In Poland there are also dozen local ethics committees which hold the responsibility for the harm-benefit analysis of project proposals. Each local ethics committee consists of researchers conducting experiments on animals, humanists and representatives of non-governmental organizations. The diversity of local ethics committees is intended to provide different perspectives on a complex issue. At the same time it is associated with some problems that may affect the quality of committee' work.
The aim of the presentation is to provide analysis of the strengths, weaknesses, opportunities, and threats for local ethics committees as a competent authority responsible for the protection of animals used for scientific purposes.

Ethics and dementia: Between quality of life and life expectancy

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Dementia is a severe common phenomenon among people living in the community. At the later stages, the cognition of the person with end stage dementia (PWESD) and his/her decision-making ability is severely damaged. In Israel, caring for PWESD living in the community and suffering from mobility constraints is mainly done by home care units (HCU). Another unique uncommon program is implemented by the home hospice unit (HHU) services, specializing in palliative end of life care. Palliative care is appropriate and beneficial for PWESD and their families, and thereby recommended by the WHO.
The aim of this qualitative study is to characterize ethical aspects, conflicts and dilemmas raised by staff and family caregivers, caring for PWESD in two care settings, with the aim of making recommendations to health organizations in the community.
Sixty-five semi-structured interviews were conducted (with 25 staff members and 40 family caregivers) in two care settings: HHU and HCU. Six main themes were identified in the interviews. This lecture describes the theme dealing with ethical aspects. Substantial differences were found in those aspects and in the characteristics of the ethical discourse between those two settings, with the main difference being the doubts and challenges in predicting life expectancy. These doubts create a gap in the expectations, approaches and goals for end of life care, for making choices and voicing preferences between **'comfort'** and **'life extension'** as the main goal. This gap creates external conflicts (between staff and families) as well as internal conflicts (staff and families among themselves).
Furthermore, this study shows the importance of developing ethical, felicitous cultural codes for professional staff caring for PWESD and their irreplaceable, significant family caregivers.
The uniqueness of this study is the comparison of two care settings for PWESD living in the community: the more common setting represented by the HCU, and the less common and less researched setting, the HHU. This information can enable us to develop ethical codes for conducting quality of care and practicing equality and mutual help for people with end stage dementia, living in their homes.

Ethnical and Cultural Factors and their Influence on Chronic Diseases in Italy: Bioethical Perspectives

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Though bodies work everywhere in the same way, ethnical and cultural aspects influence them as well. For example, it was observed that South Asians have a higher prevalence of coronary heart disease and an earlier onset of heart attack than other populations[1]. Some of the main risk factors contributing to this difference[2] (higher incidence of coronary events, higher hospitalization and mortality rates, more severe coronary artery disease, etc.[3]) show a clear bioethical interest. The first is lifestyle: South Asian people seem to consider physical exercise a selfish activity distracting people from family duties[4]. Then comes diet: typically, it is traditionally low in fibre, monounsaturated fatty acids, n-3 polyunsaturated fatty acids (omega-3), while high in sugar, refined carbohydrates, saturated fats and trans fatty acids, with a consequent increase of cardiometabolic risk[5]. The third factor is obesity: malnutrition in early childhood seemingly predisposes people to a high metabolic risk in old age and the accumulation of visceral fat, resulting in obesity[6].

Discussing gestational diabetes mellitus in a multi-ethnic population of north Italy, Caputo et al. show that High Migration Pressure Countries (HPMC) pregnant women have a worse glycaemic control, and this leads to suggest administering an insulin therapy[7]. Such predisposition could also be explained by difficulty in following the dietary advice based on Mediterranean eating habits, which differ substantially from those of non-Western countries.

Despite Italy is already a multicultural and multi-ethnic country, few studies analyse its current situation. It is therefore necessary to investigate the influence of ethnical-cultural factors in order that people may be cured and cared in the best possible way.

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Rights of patients and rights of others: how to (somewhat) ethically help when patients refuse to be patients?

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Much of the debate in psychiatric ethics in recent decades focused on reducing or eliminating coercion and changing the entire mindset of clinicians and patients as well as changing the logic of mental health care settings in order to take into account the values, the wishes and the preferences of patients. Such notions as deinstitutionalisation, community care and in some cases even demedicalisation are the most visible and are so due to many well-argued reasons. In psychiatry, as it is in medicine in general, those that need help, i.e., patients, are the experts on what helping them is supposed to achieve, while the professionals are the experts on means and ways of delivery of that help. Evidence- or values-based practice frameworks come to mind here.

There remains, however, extremely tricky area of persons who, for various reasons, refuse to engage with the system and become patients, when there are strong reasons to believe they need urgent help. In most countries there are legal frameworks that allow certain interventions in cases of danger to life and health of others. When life or health is in danger, we are ready to consider some limitation of the individual's autonomy and even when not overruling individual's decisions, then perhaps at least making sure that what we are dealing with is an autonomous decision. However, what happens when an individual seems to be unwell, but there is no immediate danger to anyone's life or limb? This topic is relatively underrepresented in ethical manuals, guidances and academic discussions.

In my presentation I would like to consider situation of persons with suspected mental disorder who refuse treatment or examination, as well as the situation of their families, friends, neighbours, and other possible interested parties from the perspectives of medical ethics, public health ethics, ethics of close-relationships and community ethics. I would like to use several examples of real-life stories and proposed solutions and scenarios.

Finally, I would like to show that respect for consent (or refusal thereof) does not always lead to the ethically least negative situation, depending on chosen perspective and to show some strategies that may be the least dubious ethically. When all answers are wrong, ethics should search for the least wrong ones.

Ethical Analysis of the Management of 2019-nCoV in Israel: Re-Mapping the Terrain

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The 2019-new Coronavirus caused clusters of severe respiratory illness and is associated with high mortality. It spread more quickly and created far greater panic across the globe than previous coronavirus pandemics (SARS and MERS), in just two months of spread. Recent research reveals that despite the (controversial, it should be noted) efforts of Chinese government and health authorities to keep full transparency and collaboration with international health organizations, two months into the onset of the outbreak major gaps still exist in our knowledge of the origin, epidemiology, duration of human transmission, and clinical spectrum of the disease.

The rapid human-to-human transmission in Wuhan China, the ability to accurately track the virus's geographical progress, and the ongoing media coverage tracing it across the globe have raised major ethical concerns, in particular given the new mobility of its human vectors and the geopolitical complexity. Among those concerns are the need for transparency and international

collaborations from the very early stages of detection and confirmation of cases. Secondly, a thorough and well-informed public discourse regarding the warranted policy of isolation of individuals at risk, which endangers the freedom to move, both on the national and international level. Thirdly, the breach of privacy by the public authority or the moral obligation of an individual to disclose their confirmed virus-positive status by either name or locations they have visited as have happened in Israel in February 2020.
I will start the presentation by reviewing the ethical issues arising throughout the management of the outbreak in Israel in light of relevant principles of Public Health Ethics such as the precautionary principle (1992) and risk perception (Nuffield 2007). Then Childress' public health ethics framework and public health principles (2002) and Marckmann et al. framework (2015) will be examined and applied to the case at hand. I will demonstrate how the policy guided by the Israeli Health care authorities to protect the public from coronavirus pandemic were not justified by most ethical principles. Moreover, I will argue it was highly influenced by non-evidence-based factors and public pressure rather than by a well thought ethical discourse taking into account relevant principles and frameworks as well as existing body of scientific knowledge.

Half a Century of Bioethics and Philosophy of Medicine. A Topic-Modeling Study
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A standard way in which practitioners of an academic discipline reflect on the history and development of their own discipline is through “close reading” of selected texts, which is often mediated through their personal experience and academic interests. This approach is visible in the classical books about the history of bioethics (Jonsen 2003) or important articles that try to identify “the hottest topics” during the development of the field (Veatch 2006). Here is a typical statement identifying trends in bioethics based on such approach: “Over the course of the history of bioethics certain topics have moved in and out of fashion: in the 1970s it was euthanasia and abortion, in the 1980s genetics, in the 1990s stem cells and reproductive technologies, and in the 2000s, enhancement and data/tissue storage” (Dawson 2010). However, ”close reading” as a way to detect very general trends in the literature is sometimes treated not only as not-replicable and suffering from underdetermination by evidence (i.e., different interpretations may easily be drawn on the basis of the same material), but first of all as non-transparent and using arbitrary sampling when working with a large corpus (see Pääkkönen and Ylikoski 2020 for discussion of such criticisms).
In contrast, a different approach – the one we further in this article – takes seriously an epistemological question on how one can justify a belief that, for example, in the 2000s the issue of “enhancement and data/tissue storage” dominated the debate. We employ a “distant reading” (Moretti 2013) approach based on topic modeling – a computational text-mining technique aimed at discovering hidden thematic composition in large text corpora. In this study, following similar analyses conducted in other areas of philosophy (Malaterre et al., 2020), we construct a corpus of 19,488 texts published since 1971 in seven leading journals in the field of bioethics and philosophy of medicine (as identified by experts in the field). The latent Dirichlet allocation (LDA) algorithm, which we use in this study, identifies ‘topics’ – sets of words that tend to be used together across documents in the corpus (Blei et al. 2003). Those topics are chiefly characterized by relatively small sets of words most strongly associated with them and, thus, it is typically easy for the researcher to interpret them, that is, to associate topics with actual, discrete themes discussed in the analyzed collection of texts. For instance, if the model’s output includes a topic characterized by terms ‘gene’, ‘therapy’, ‘clone’, ‘disease’, ‘germline’,

we can reasonably straightforwardly interpret such a topic as latching onto the classical debate on germline modification and gene therapy.

On the basis of inter-topic correlations, we group the content-based topics into 8 clusters, thus providing a novel, fine-grained intellectual map that represents the diversity of bioethics and philosophy of medicine. Moreover, we conduct a number of diachronic analyses, examining how the 'prominence' of different topics changed across time. This way, we are able to observe distinct patterns in which bioethics and philosophy of medicine were evolving and changing their focus throughout the past half a century.

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