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ABSTRACTS

Managing genetic conditions in sperm donor conception: ethical and methodological challenges

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Assisted reproduction is a complex and rapidly evolving field that poses significant ethical and methodological challenges. One of these challenges relates to the management of (suspected) genetic conditions in sperm donor conception. Current practice involves screening potential donors for a limited number of genetic conditions including, for example, cystic fibrosis, sickle cell anemia, and spinal muscular atrophy. Taking into account the prevalence and severity of a condition, this threshold-based approach accepts a certainA level of risk. However, a gray area emerges when it comes to using a semen sample from a donor who is found to be a carrier of a recessive condition, for instance after a child is born with a very rare genetic condition not included in routine screening. Although the risk (i.c. for a second child with this genetic condition) may be far below the accepted threshold for screening, some clinics exclude the donor to avoid potential ethical (and legal) issues.
While this decision may seem overly cautious or even irrational, it can be understood from a clinical perspective. For instance, they may be concerned about the perception of using a donor who carries a risk for a known genetic condition. Indeed, using such a donor could open them up to criticism or legal action if a second child (in a different family) is born with the same condition, as the clinic can then be accused of 'knowingly' having put the future child at risk. Such a claim, however, would commit to acknowledging a morally relevant difference between knowing that there is a general risk for genetic conditions and knowing for what specific condition there is a risk (while the degree of risk is identical). Balancing these considerations with parental desires and a fair distribution of scarce resources in assisted reproduction is a complex and nuanced decision-making process.
The grounds for excluding a donor in this situation raise important questions about the role of ethical guidelines. For instance, should ethical guidelines be adjusted to account for merely pragmatic considerations or biases in risk perception (e.g. being more cautious for specified risks), or should rational decision-making prevail? We argue that an interdisciplinary approach is necessary to develop a comprehensive and ethically sound framework for managing genetic conditions in assisted reproduction. This framework should take into account the interests and lived experiences of different stakeholders, including (potential) donor-conceived persons, recipients, donors, and clinics. Overall, this analysis contributes to debates on methodological problems in bioethics, particularly regarding the role of ethical guidelines and the balance between rational, practical, and emotional decision-making.

Re-framing and re-building the unit of analysis in ELSI/A-frameworks

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ELSA/I frameworks have been criticized for having the unit of analysis in technologies as instrumental artefacts. This approach lacks acknowledging the historical, social, cultural and political context in which the technology has been developed, disputed, accepted, validated, and prioritized. Consequently, bioethicists have been accused of serving the "business-as-usual", (intentionally or unintentionally) reinforcing linear views of progression of science taking for granted the law-like nature of the current economic paradigm in which modern technology-development situates. Furthermore, applied technology ethics in general and across disciplines, has suffered from a polarization of optimist and pessimist views on what to think

about the role of technology in making the world a good, or better, place. This polarization complicates discussions by creating thick attributes of rationality and irrationality between parties. In this paper I will suggest concrete methodological remedies for a framework that assesses the ethical, legal and social aspects and implications of emerging technologies. This is done by transferring the unit of analysis to technology as a sociotechnical system and incorporating an evaluation framework for the technologically optimist (or pessimist) argumentative chains.

Postcovid syndrome – etiology, uncertainty, ethics

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The over two years of pandemic brought about a flood of research on covid-19, which presumably has contributed to the quick development of vaccines and medicines against the disease. The impact of the pandemic was unprecedented in almost all areas. It soon became clear that not all who had gone through a covid19-infection recovered as expected. Their recovery was more or less delayed, and symptoms lingered on for many months, or even longer. The concept "post covid19 - syndrome" was established, but there is still a considerable terminological uncertainty. When this syndrome became known, research started also on this group. The results, however, are very hard to interpret. No obvious relationship between pathophysiological findings and symptoms is found. Prevalence and clinical course vary widely. Also, the symptoms show similarities with other enigmatic syndromes, like ME (myalgic encephalitis) and CFS (chronic fatigue syndrome), where etiology and treatment are both uncertain and controversial.
A number of ethical challenges arise in relation to postcovid. These are inevitably partly dependent on the uncertain conjectures concerning its nature. As covid-19 is seen as a tough, potentially lethal, disorder, there is an inclination to view the etiology of postcovid as clearly somatic – be that induced autoimmunity, tissue damage during infection or immunological overreaction. But given the symptom spectrum and the very weak relation to infection severity, the symptoms may well, more or less, be due to "somatization", that is: due to the psychological/existential impact of going through a covid-19 infection. However, to distinguish these two etiological categories in order to give the right treatment seems very difficult. Also, persons with postcovid almost without exception reject any suggestion that their symptoms might not be due to somatic damage, but rather psychological factors.
Against this background, a number of sensitive ethical question arise. Many of them are due to the fundamental uncertainty concerning the nature of postcovid. Also, ontological questions come in focus, when different aspects of disease – illness, disease, sickness – are in tension. I will outline some of these ethical dilemmas and hint on possible ways of dealing with them in order to support a patient group with often great suffering.

Blood donation and banking in Kolkata- it's roadmap, imagery and fantasy

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Blood stands out as a concept which intrigues imagination beyond the boundaries of anatomy. It runs as an idea of inheritance and power. The liquid substance is a social metaphor, underpinning the basic rules of association, division, heredity, hierarchy and oppression. The act of its donation to save another life enables fantasticating a wide spectrum of imagery of the

body fluid. In case of voluntary blood donation and banking the very medical procedure can be studied as a roadmap from political history (the association of military wars and the rising need for technological and medical evolution in blood transfusion and banking methods), personal memoir (the urge to donate blood in case of familiarity donation or donating in the name of a political hero) to political culture (the regimented blood donation camps organised to commemorate political agenda or efficacy). The objective of this study is to closely observe this complexity of the voluntary act of blood donation and banking in its established political rituals in the Indian city of Kolkata. In 1942 India saw its colonial rulers set up the first blood bank of the country in Kolkata during World War II. Two decades later, the city, among the very few others, helmed the national movement for delegitimizing remunerated blood donation and promoting voluntary blood donation. Currently it is the city with a great number of voluntary blood donation camps held every year in India. Therefore, the city of Kolkata is our chosen site for the research.

This study will highlight the act of blood donation in facilitating political efficacy or functionality while blood building a morality of virtual kinship and commemorative altruism in a community. The specific objective of donation may be relevant till the donor is donating blood but after donation it travels its own journey towards the outward, abstract anywhere. There remains a certain abstraction within specificity. The argument which comes out is that the local political culture of Kolkata, apart from broad and remote political decisions which have already affected blood procurement and management in India, affects the process and creates meanings through symbolic rituals which are foundations of a set of ideological and political morality that is to be infused in the population. The directionality of local political culture is to create and reuse these rituals in order to generate political merit for them in the society. The stake of the state is no different from the daily political culture, it manifests the paternalistic authority who validates the infusion of 'centrifugal' true altruism in case of blood donation and wants to execute it to create an archetypical 'centripetal' action which will repeat itself in every transaction of blood as a normative construct.

It is qualitative research using the methods of in-depth interview and participant observation. The researcher interviewed governmental and non-governmental stakeholders (including People's Blood Bank, Calcutta National Medical College and Hospital Blood Bank, etc) of blood banks in the city. The researcher participated and observed the process and donors and agendas in three different voluntary blood donation camps organised by separate groups. The researcher also reviewed the documentation of the history of blood donation and banking in the city from already published material and interviews conducted with the officials at the Association of Voluntary Blood Donors Kolkata. The collected data was then analysed using narrative analysis and discourse analysis techniques.

Evaluating Human Epigenome Editing: Methods for Risk Assessment and Methodological Challenges for Bioethics

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The goal of this talk is twofold: On one hand, we ethically evaluate human epigenome editing (EE), a novel gene technology that could up-/downregulate gene expression at will. The ethical debate about EE is scarce, and shows a tendency to portray EE as less risky than genome editing (GE). We argue that EE can be just as risky for those whose epigenomes would be edited in a clinical/research setting as somatic GE, or even germline GE. We defend this position by suggesting a new method for risk assessment of gene technologies. This method uses the following list of criteria that should be evaluated for estimating potential risks: timing (when is

editing done, e.g., during embryonal/foetal/neonatal stage/in child-/adulthood); targeted diseases and available treatment for potential side effects that might follow editing (if neurological/neurodevelopmental disorders are targeted, side effects are presumably both more likely to be irreversible, and more severe); where the editing is done, inside the body (*in vivo*), or outside the body (*ex vivo*/*in vitro*), the latter coming with fewer risks, but less effectiveness, and diminished feasibility. We therefore argue that EE cannot be generally regarded as safer than GE, since risks will depend, for both techniques, on the factors outlined in the description of the criteria. We also argue that EE of germline cells is an unlikely scenario, and would not be heritable, but nevertheless of interest for ethical/legal debates of EE. We then suggest that future ethical discussions about EE should put special focus on assessing applications in a preventive setting that come with challenges such as new expressivist arguments (by attempting to prevent conditions like autism not always understood as a disease), and medicalization or epigenetically based discrimination. The first goal of the talk is, thus, jumpstarting an ethical debate on EE, which is one of the objectives of a bioethical research project on EE and GE, which we worked on together as two philosopher-bioethicists. On the other hand, as the second goal of the talk, we want to highlight benefits of interdisciplinarity within philosophical-bioethics, associated challenges, and suggest some measures to alleviate the challenges. We integrate this second objective into the first one, and present the results of our research project as specified above, and with reference to the specific methodological challenges; this is based on an article commentary we have recently published on Blumenthal-Barby's et al. paper "The Place of Philosophy in Bioethics Today." An issue is the knowledge-translation between disciplines, another different publishing cultures. We recommend addressing challenges associated with indispensable interdisciplinarity in bioethics so that interdisciplinarity doesn't hinder academic research and academic careers, e.g., because of time-consumption for acquiring knowledge in special areas across several disciplines incompatible with funding-schemes for many bioethics-projects, and differences in publishing cultures between disciplines challenging for academic qualifications. We suggest that measures for alleviation must be discussed, such as creating travel-funds for young bioethicists for attending oftentimes international conferences in several research areas (philosophy; bioethics).

Challenges and benefits of implementing open science practices in clinical trials: transparency, reproducibility, and ethical conduct.

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Open science, which encompasses a range of initiatives aimed at making scientific research more transparent, accessible, and reproducible, has gained momentum in recent years. The aim of this presentation is to provide a brief overview of the current state and impact of open science practices in the field of clinical trials.

The presentation also explores the benefits of open science in clinical trials, such as improved data sharing, as it increases collaboration between scientists and facilitates faster progress in research. Open science also increases transparency, which can enhance the credibility and impact of research. Besides, open science leads to better patient engagement and more patient-centered research outcomes. These practices can enhance research efficiency by reducing duplication of effort and improving the use of resources in clinical trials. Not the least - open science practices can help build public trust in the scientific process and foster greater public engagement in research.

Despite the mentioned benefits, open science also faces some serious challenges related to the protection of patient privacy and the ethical use of research data. From the methodological point

of view, open science practices are still in their infancy. There is a lack of standardization across research studies, making it difficult to compare and combine data from different studies. Open science is not yet widely adopted in clinical trials, which can limit its impact and potential benefits. Besides not being well developed, it requires time and resources to be implemented and maintained, which can be a challenge for scientists and research institutions. Still, another challenge is that open science can lead to the misuse of research data or findings, particularly in cases where data is misinterpreted or used inappropriately.
Besides the issues already mentioned, this presentation examines the role of open science in reproducibility and the need for more diverse and inclusive research practices.
Finally, recommendations for promoting open science practices in clinical trials, including developing policies and guidelines for educating and training researchers in open science practices, are offered.

Augmenting and Accommodating Accessibility: Policy Generation through the Picture Theory of Disability at Post-Secondary Institutions

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While questions of equity, diversity, and inclusion (EDI) and accessibility are becoming priorities for post-secondary institutions world-wide, institutional policies that support and advance these goals rarely succeed in adequately defining and responding to the needs of individuals experiencing disability — thereby limiting the ability of people experiencing disability to fully participate in their academic experiences.
Post-secondary policies dealing with accommodation and EDI often revert to a biomedical definition of disability or need, and Harmon points out that, "little effort is made to design effective and meaningful feedback loops to help healthcare providers make better decisions or design better systems;"[1] this applies equally to education providers as healthcare providers when they consider how to enhance participation in education by people experiencing disability. Harmon also argues that "the embodied experiences of stakeholders can be used to aid reflection, analysis, and the development and implementation of normative guidelines applicable to given practices."[2] Thus far, post-secondary policies do not often fully take advantage of the opportunity to draw on such stakeholder experiences.
The Picture Theory of Disability[3] (PTD) provides a more complete, inclusive way to give agency to individuals experiencing disability in terms of having their lived experiences recognised in policy development and application. By allowing for a more complete understanding of a person's lived experience, academic institutions would be able to identify supports and improve accessibility for individuals, thereby more meaningfully increasing accessibility and EDI.
Drawing on the interaction of bioethics with philosophy, public policy, and law, we present a case study of accessibility and accommodation policies at the University of Lethbridge and other public post-secondary institutions to consider where the efficacy of existing policies could be improved by the use of PTD in determining eligibility for and the nature of accommodations. Improving the policy approach to questions of disability will be one step in making post-secondary education fully accessible for individuals experiencing disability.

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[2] Ibid.
[3] Firth, Steven J. The Picture Theory of Disability. Forthcoming in *Cambridge Quarterly of Healthcare Ethics*. 2023

What is it like to be a brain organoid?

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Brain organoids are three-dimensional neural cell aggregates, grown from pluripotent stem cells, that recapitulate some of the functions and structures of the developing brain. Currently they can be as large as a lentil and consist of up to 2–3 million neurons and glia cells. This is only a fraction of the size and complexity of the human brain, but considerably larger than the brain of a fly. As brain organoids become larger and more complex, and different types get assembled to approximate better the structure of the human brain, we may, on purpose or by accident, create sentient or even conscious beings. A further moral complication follows from implanting human brain organoids in non-human animal brains. Here I will discuss the relationship between cognitive capacities and moral status, with a focus on the problem of assessing the capabilities of brain organoids for sentience or consciousness, as well as the question whether brain organoids could have subjective experiences which cannot be captured by any physical measurements, and the ethical implications of that.

A Dialogical Approach in Bioethics

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In bioethics moral reason is brought to bear on issues in healthcare, human research, and health policy (McMillan 2020). In this presentation, the focus will be on what it implies to "bring moral reason is to bear" on these issues. It is argued that a fruitful way to deal with many of the challenges facing us is to adopt a dialogical approach in bioethics.

It is a defining characteristic of a dialogical approach that it focuses on the communication which takes place in the handling of moral issues. Theoretical reasoning should take into account that the issues will be dealt with by health care professionals, researchers, and policy makers in their interaction with patients, research participants and citizens. This means that a dialogical approach is contrasted with monological approaches where the reasoning power of the bioethicists and their take on the issues is primarily in focus. This also means that a dialogical reasoning is contrasted with instrumental reasoning where the emphasis is on finding the most efficient means to a desired end.

A dialogical approach is not regarded as a distinctive mode of reasoning or alternative to other approaches in bioethics. The main emphasis is placed on the way in which people meet each other in conversations of moral relevance. This implies that a dialogical theoretical reasoning is concerned with procedures which are likely to bring about fair communicative practices. It is also pluralistic in the sense that the conversation partners bring with them their normative ideas which are rooted in their ethical lifeworld. This shows kinship with the idea of "common morality". In a dialogical approach, no attempt is made to predetermine the content of common morality but presumed that people tend to share certain moral intuitions that are related to basic human interests.

The appeal to common morality in principled bioethics does not place this trust in the actors themselves. An attempt is made to create an analytical framework with substantial principles "to provide a suitable starting point for reflection on moral problems in biomedical ethics" (Beauchamp and Childress 2019, p. 13). This is characteristic of the monological tradition in bioethics where the main emphasis is on the substantial principles, rules, and virtues but little attention is paid to the way in which issues are discussed with patients, research participants and citizens. The controversy surrounding principlism tends to focus on whether the principles

selected in the theory are the right ones, whether they are properly prioritized, how they are often rigidly applied and culturally biased. My concern is about the neglect of the way in which the norms of common morality are handled in communicative practices in the different relational contexts.

Phenomenological approach in exploring vaccine hesitancy

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There is a strong scientific consensus that vaccination has become one of the main means to control infectious diseases in human populations. However, the global vaccination efforts are met with growing scepticism, also known as vaccine hesitancy (defined by WHO in 2015). Vaccine hesitancy was also one of the major challenges in the context of the Covid-19 pandemic, opening up several important questions for bioethics.

Vaccine hesitancy has been studied worldwide from sociological and psychological perspectives resulting in numerous research studies. However, current empirical studies lack comprehensive, in-depth explanation of the embodied experience of the vaccine hesitant-behaviour. Phenomenological approach offers such a framework.

In this paper I will report on the progress and intermediate results of our ongoing research project "Hesitant bodies: phenomenological analysis of the embodied experience of vaccine hesitancy" and will reflect on methodological issues concerning the use of the phenomenological approach in empirical studies.

Methodology The project is situated within the field of medical humanities, and draws on theoretical as well as methodological insights from the phenomenological philosophy. This is phenomenologically informed qualitative empirical research study. In the project we have conducted semi-structured interviews with adult participants, who consider themselves to be vaccine hesitant (N = 16). By using conceptual framework (such concepts as embodiment, intentionality, life world, body image, body schema, alienation, temporality, normality etc.) we intend to gain knowledge about the embodied experience of vaccine hesitancy and to uncover the structures of this experience.

In the presentation I will focus on two important methodological tools applied in the project. The first, 'phenomelogical interview' which is a framework that integrates the qualitative interview with phenomenological philosophy (Høffding and Martiny 2016), ensuring both a strong conceptual framework and methodological tools. The second, 'factual variation' that allows cross-fertilization of already established phenomenological concepts and themes generated from the interview material (Froese and Gallagher 2010).

Discussion part may include sevaral important methodological questions – on internal and external validity of phenomenological methodology for the empirical research? What are the limitations of 'phenomenological interview'? How to asses the role of the embodied experience in decision-making process regarding vaccination? Etc.

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A dialogue between empirical bioethics and field philosophy in the French-speaking context

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Empirical approaches to philosophy are growing around the world, although they consist in different approaches and use various names. Indeed, there are almost as many forms of empirical bioethics as there are researchers who claim to use them: Rachel Davis and her co-authors for instance have listed at least 32 distinct methodological approaches.[1] The intellectual paths of its representatives and their research objects, as well as the factors that condition them in context, from traditions of thought, to academic systems, to public policies, shape a diversity of philosophical movements that value a certain relationship to experience. In this contribution, we will establish a dialogue between two philosophical movements: field philosophy (*philosophie de terrain*), as it is emerging in France and other French speaking countries, and as we ourselves practice it, [2] and the version of empirical bioethics formalized by Jonathan Ives at the University of Bristol.[3]

While empirical approaches are currently in vogue in the French speaking context, in particular among young researchers, they currently meet a strong institutional resistance within the discipline which is still dominated by a focus on the history of philosophy as well as from researchers in the human and social sciences. This controversial place has however given researchers in philosophy a certain tolerance in methods, orientations, tools and references from which they can benefit and has allowed for development of tailor-made research projects, in which the most appropriate methods may be experimented and discovered in the field.

Without trying to oppose these approaches in a binary debate, our objective in this contribution will be to determine what these different approaches (the French perspective and the perspective of empirical bioethics developed by John Ives) imply for the practice and the place of philosophy. Three points will be of particular interest to us: the method in an interdisciplinary context, the tension between descriptive and normative conceptions, and the prerogatives assumed or assigned to the philosopher in the field.

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[2] M. Benetrau, M. Bérard, B. Bogaert, D. Delorme, et M. Dubar, *Manifeste pour une philosophie de terrain*, Dijon, Éditions Universitaires de Dijon, 2023.

[3] J. Ives et H. Draper, « Appropriate Methodologies for Empirical Bioethics: It's all Relative », *Bioethics*, vol. 23, n° 4, 2009, p. 249-258.

The normative role of stakeholder engagement in empirical bioethics: a methodological reflection on the use of stakeholder meetings in thinking about access to expensive anti-cancer treatments.

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Empirical bioethics is a fast-emerging field within bioethics. Over the past few years, researchers have tried to solve the is-ought problem by designing methodologies for bridging the gap between empirical findings and normative recommendations, also known as integrated empirical bioethics. They have pointed out the importance of a sound methodological process in regards to the normative justification of moral recommendations. For instance, the Bristol Framework distinguishes 3 phases within an empirical bioethics project; the phase of the mapping of the field (for instance with a literature study), framing (further exploring the field,

for example by conducting qualitative interviews) and the phase of the shaping of the field (bridging the gap between empirical findings and normative recommendations) (Huxtable, 2019). There are roughly two kinds of overarching approaches in integrating the empirical and normative work within empirical bioethics: the consultative approach and the dialogical approach (Davies, 2015). In the consultative approach, the normative analysis takes place after stakeholders are consulted, for instance when researchers develop normative recommendations after analyzing qualitative interviews. In the dialogical approach, normative claims are developed during the interaction with stakeholders, often seeking a shared understanding. While multiple researchers have written about procedural aspects and justification of the dialogical approach in empirical bioethics, little research has been conducted regarding a methodology to engage with a diverse group of different stakeholders in developing normative recommendations. In this paper, we provide a methodological reflection on the use of multiple stakeholder meetings within a research project in the final (shaping) phase to integrate the empirical and normative. We have organized sessions with a diverse group of stakeholders (physicians, patients, insurers, pharmaceutical companies, hospital executives and policy makers) on access to expensive non-reimbursed anti-cancer treatments. The aim of these sessions was to extrapolate normative recommendations involving a diverse group of relevant stakeholders. To do so, we have used a combination of an adapted nominal group technique and a dialogical hermeneutics approach. In this paper, we provide a methodological reflection on the conduction and normative role of these meetings in deriving normative claims.

The ethics of mitochondrial replacement techniques for treating infertility

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In mitochondrial replacement techniques (MRTs), nuclear DNA is transferred from an oocyte or zygote to an enucleated donor oocyte before or after in vitro fertilization (IVF). This usually aims to prevent the transmission of maternally inherited mitochondrial diseases caused by mutations in mitochondrial DNA, which is located in the oocyte's cytoplasm. These techniques can also be applied to treat infertility, especially for older women with impaired oocyte quality who have not been able to achieve pregnancy via conventional IVF. This application of MRTs has received insufficient attention in the medical ethics literature so far.
Until now, specific legal regulation of MRTs has been implemented in the UK and in Australia. In both countries, clinical trials on these techniques are only permissible for cases with a high risk of severe mitochondrial disease in the offspring. However, in some countries without legal regulation of these techniques, MRTs for treating infertility are already offered by fertility clinics.
Restricting the use of MRTs to the context of hereditary mitochondrial disease, as is the case in the UK and Australia, implies that there are medical or ethical reasons to treat this application of MRTs differently from their application as an infertility treatment. If there are no such reasons, the legal regulations in the UK and Australia seem inconsistent.
The permissibility of clinical trials on a novel medical procedure generally depends on whether the (potential) harms of that procedure are justified in relation to its potential benefits, and whether there is enough scientific evidence to assume that the procedure can achieve its aim. Allowing MRTs in the context of mitochondrial disease but not for the treatment of infertility might thus be justified either because their application in the context of mitochondrial disease 1) has a lower risk, 2) is supported by a more convincing evidence base or scientific hypothesis, or 3) has a higher potential benefit.

In this talk, I will compare both applications of MRTs with respect to these three factors. I conclude that there seems to be no convincing reason why clinical trials on MRTs as an infertility treatment should be prohibited if they are permitted in the context of hereditary mitochondrial diseases.

Dynamic Consent: A Royal Road to Research Consent?

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Informed consent is a central principle of biomedical research ethics. However, since the late 20th century, the principle of informed consent has been seriously challenged by technological advances enabling the long-term storage, sharing, and use of people's samples and data beyond the initial purpose of collection. While further useability is a central demand of modern research, obtaining valid consent from participants proves challenging in the face of the unpredictability and sheer amount of possible future applications of stored resources.

In this context, the concept of broad consent has been conceived as a way of obtaining participants' one-time consent to a broadly defined range of future research uses. However, while this facilitates research, some have argued that broad consent fails to constitute meaningfully informed consent (Hofmann 2009, Kaye et al. 2015) or that it would not provide the level of control necessary for authentic self-determination (Caulfield 2007). This has fostered the emergence of so-called dynamic consent as an alternative model to broad consent. Dynamic consent allows participants to stay informed about new research activities and provides them with a level of fine-grained control over their involvement in individual research projects (Budin-Ljøsne et al. 2017, Biasiotto et al. 2021, Teare at al. 2021).

Dynamic consent has generally been welcomed as a morally praiseworthy approach to helping participants regain control over their involvement in research. Negative voices are few and focus mainly on challenges around its implementation. However, critics have not had much to say about the main moral argument in favour of dynamic consent, namely that it would do better than broad consent in promoting participant autonomy ('the autonomy argument'). This paper aims to fill this gap.

The paper identifies two versions of the autonomy argument. The information-focused autonomy argument holds that dynamic consent better promotes participant autonomy because it allows the consent-giver to be sufficiently informed about all the research activities to which she might potentially contribute. The paper uses the distinction between disclosure and understanding of information to argue, against this, that dynamic consent is based on a certain implausible view on how much the consent-giver needs to understand in order to give valid consent. The control-focused autonomy argument holds that dynamic consent better promotes participant autonomy because it allows the consent-giver to control whether she contributes to any individual research activity. Against this, the paper argues that dynamic consent is based upon a certain defective view about the moral status of consent preferences which holds that, since there is no general obligation to contribute to research, a participant's refusal to contribute to any individual project is always morally permissible. The paper looks at cases of arbitrary, discriminatory, and otherwise morally objectionable consent choices to reject this view and argues that there are conditional obligations to support research that dynamic consent fails to account for. The paper concludes that instead of adopting a dynamic consent model, we should think more about the possible function the principle of informed consent could fulfil in the social practice of modern biomedical research.

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Bioethics of somatic gene therapy: What do we know so far? A qualitative systematic review

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Many preclinical and clinical studies are investigating the therapeutic potential of somatic human gene therapy. However, the extensive research efforts are accompanied by unresolved ethical discussions. My aim in this presentation is to provide an overview of the bioethical debate on somatic gene therapy as documented in the scientific literature. To do this, I will present a systematic review in which were included publications containing at least one bioethical argument about human gene therapy. Articles were analysed using two data extraction documents, one for descriptive information and the other for arguments. A meta-synthesis was performed to analyse the data.

The search strategy retrieved 1621 references after removing duplicates and 217 were identified as eligible publications. We extracted 189 different types of arguments. The arguments were divided into 23 categories. Twelve were research-related, including risk/benefit, priorities and limitations, informed consent, review, and monitoring. Eleven were societal, including population impact, human identity, public perception, human health. Public input was mainly mentioned in relation to the research process, review and monitoring, the debate on priorities and limits of research, and the debate on the ethical and social dimensions of somatic gene therapy.

The arguments need to be re-evaluated before somatic gene therapy becomes a large-scale intervention.

Participant Observation as a Method for Empirical Bioethics

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For some time now, methods of empirical social research have been increasingly applied in bioethics. Some authors speak of an "empirical turn" in bioethics in this context. The aim of empirical research in bioethics is, among other things, to involve different stakeholders in the research, to make the perspectives of affected people and in particular of vulnerable groups visible, and to compare the perspectives of different stakeholders in order to arrive at a well-founded ethical judgment. In addition to quantitative surveys, qualitative social research in the form of interviews or group discussions is primarily used here. This means that empirical research in bioethics has focused primarily on what people say and less on what people actually do.

As a form of applied practical philosophy, however, bioethics cannot afford to solely focus on what people say and ignore what people actually do. This is all the more important since what is said often differs from what is actually done. The subjective perspectives of the participants expressed in interviews can be subject to distortions. This may be because they do not fully perceive the situation or because they express themselves in accordance with socially desirable behavior or conceal aspects out of shame. In the case of psychiatric and neurocognitive disorders like dementia, there is also the problem of a lack of insight into the disease, which sometimes makes an open interview even more difficult. Thus, the focus on opinion-oriented research runs the risk of distorting empirically informed ethical judgment. Therefore, this talk explores the potential value that participant observation as another method of qualitative social research offers to empirically informed bioethics.

We discuss the method of participant observation on the basis of examples from computational neuropsychiatry. We conduct participant observations of physician visits and, in particular, medical briefings to investigate the influence of AI-based approaches on the role of the physician, the patient, and their relationship and interaction. Observations will be documented in corresponding observation protocols and analyzed with respect to models of the doctor-patient relationship and standards of shared decision making. In addition to a brief presentation of initial results, we will primarily reflect on the possibilities and limitations of this observational method. In each case, we will reflect on the demands that conducting participant observation places on the researchers. What kind of setting is necessary? What are the special requirements especially in bioethical research? What kind of information do the patients need beforehand? We show that participant observation is a particularly demanding empirical method which requires careful preparation and training of the researchers, especially in a medical context and in a clinical treatment situation that is central for the patients. We argue that it offers the possibility to illuminate the clinical and nursing practice and the interaction between physician and patient from a different perspective and therefore to make judgments of empirically-informed bioethics more well-founded. Hence, we conclude that participant observation is a necessary complement to empirical bioethics with high insight value if it is sufficiently prepared and properly conducted.

Ethical analysis of the management of biological samples and personal data in mass disaster for identification purposes.

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Mass disaster situations generate a large number of human deaths, as well as grave social and administrative disruption. Tracing the missing and identifying the dead are crucial to maintaining or restoring basic human rights and responsible relief activities. In some cases the bodies and body parts of dead persons thus remain the object and subject of a variety of forms of moral, legal and scientific rulings for unexpectedly long periods of time. Sometimes unidentified bodies remain mysteries, anonymous case numbers that create what the national Institute of Justice calls a "silent mass disaster". The successful identification of victims constitutes not only a State interest, but also humanitarian and emotional priorities. Identification is necessary in the reduction of uncertainty and as part of the mourning process of relatives and friends, as coping or as closure, considering that a "reverential" treatment of bodies is part of this process. Thus, identification is not only an organizational and scientific achievement but, regardless of circumstances, it is also necessarily and always an activity with significant political, epistemic and philosophical relevance and consequence.
As some authors debate, biological death was not the same as social death and that there were posthumous interests of the dead (what people care about is what happens to their bodies, and most of us think that people should be able to determine what others are allowed to do to their bodies), their families, and their communities to consider. In fact, the physical death of individual subjects does not immediately mark the end of their personal and social identity trajectories. The many ways in which we continue to interact with, or invoke, past persons and their material bodies continue to shape and answer to their post-mortem identities. We can defined "posthumous interests," as the interests that living people have in what happens after they die, however, the posthumous interests view is not the only potential foundation of an obligation to respect the dead.
Another aspect considered regards the application of artificial intelligence (AI) to the identification of bone remains. In the field of forensic sciences, AI applications could contribute to enhancing It is essential to reflect on whether the implications of AI are actually going to replace and diversify or complement and expand previous well-known solutions to problems.
The aim of this work is to explore and share ethical considerations regarding the identification of human remains in the event of disasters, considering that the successful identification of victims contributes not only to state interests, but also to addressing humanitarian and emotional priorities.

Rethinking the core values endorsed within a Philippine medical school

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This paper presents our ongoing research program that explores the core values endorsed within St. Luke's Medical Center College of Medicine-William H. Quasha Memorial (SLMCCM), a private medical school in the Philippines. Core values constitute fundamental commitments that persons or organizations believe are important to influence how they ought to live and work. In a higher education institution (HEI) such as a medical school, core values are frequently assumed to guide organizational culture, practices, and curricula. However, there is much to be explored about whether and in what ways core values are understood and experienced by HEI stakeholders at various levels (e.g. personal, professional, organizational). To establish and

respond to this question, we launched ‘Balay Lukan’ (House of St. Luke's) to examine the core values endorsed within SLMCCM, as perceived by its key stakeholders.
The project is implemented in two phases. Phase 1 identified specific core values and their practical applications. We conducted ideation workshops eliciting specific examples of core values translated to specific practices (e.g. attitudes, behaviors). A broad spectrum of clinicians, teachers, students, support staff, and patients contributed to these workshops. We described what behaviors linked to core values (e.g. stewardship, professionalism, integrity, commitment, excellence) can be encouraged or questioned. Phase 2 will be implemented later to provide recommendations for considering the reformulated core values in organizational development and curricular reform. This project is important for two reasons: First, it offers a systematic approach to translating philosophical concepts (values) into practical outcomes (behaviors). Second, it seeks to develop knowledge that can support or even challenge existing values chiefly adopted in medical schools and clinical training. Overall, the project demonstrates the usefulness of a bottom-to-top approach in exploring broad values relevant to health professions education, with implications for theoretical advancement and meaningful applications.

Understanding and use of implied and presumed consent by healthcare professionals in South Africa: An empirical mixed-methods study

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Background: Inferred consent is sometimes relied upon by healthcare professionals (HCPs) to conduct patient treatment procedures. However, the extent to which one may infer treatment is somewhat controversial, given that the HCP cannot determine a patient’s state of mind at that particular point in time. It has been suggested that consent can be inferred from a patient's conduct and behavior, which may permit interference with the patient's right to self-determination.
However, it has also been argued that implied consent can be viewed as a form of estoppel, whereby one can presume, based on a patient's conduct in a given circumstance, that one could reasonably conclude that the patient has consented to treatment. In such cases, the patient will not be permitted to claim afterward that they did not consent to the said treatment or interference with personal autonomy, and HCPs may have a defense against battery based on the patient’s behavior and apparent consent.
However, some authorities have cautioned that a patient's silence alone does not constitute a treatment agreement. In all cases, the issue should be based on a reasonable deduction based on the patient's conduct at the time or anything else known about the patient.
Methods: This questionnaire-based study evaluated the understanding and application of implied/presumed consent among doctors and nurses practicing at South African public hospitals. The questionnaire included itemized and open-ended questions on understanding implied/presumed consent use during clinical practice. Data were analyzed using SPSS v20-22. Quantitative data were summarized using descriptive statistics and qualitative by content analysis.
Results: Five hundred and twenty-three HCPs completed this study (168 doctors and 355 professional nurses) and were asked to explain how much they used implied or presumed consent during clinical practice. Here, 65% of doctors and 57% of nurses said they used it when the patients showed up at the clinic or were admitted to clinical wards. Most HCPs were likelier to use implied/presumed consent in emergencies (43%). Regarding how often they used implied or inferred consent in practice, 59% of doctors and 43% of nurses said they used it ‘rarely.' Another 24% of doctors and 40% of nurses said they ‘never’ used implied/presumed consent,

while 11% of doctors and 16% said they used it 'all the time.' When asked to describe their understanding of implied/presumed consent, many doctors and nurses suggested that when a patient showed up at the clinic or the doctor's office for a consultation, this automatically implied 'seeking help' by the patient, and the HCP could presume that the patient was consenting to treatment. Open-ended questions regarding the understanding of implied and inferred consent by doctors and nurses elicited responses such as: "By routine of the patient coming to the healthcare facility- he is consenting to treatment."
Conclusion: Responses from HCPs in this setting suggested a misunderstanding of the concept of implied and presumed consent by many HCPs practicing in South African public hospitals. The study also showed characteristic elements of medical paternalism during clinical practice, which has the potential to compromise patients' autonomy.

The COMMUNI.CARE Protocol: an interdisciplinary approach to convey severe diagnosis
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In the study protocol COMMUNI.CARE (Consolandi et al. 2020), we analyzed the interaction between the physician and the patient at the moment of severe diagnosis using an innovative interdisciplinary approach; in particular, we focused on the diagnosis of pancreatic ductal adenocarcinoma (PDAC). The main goal of the study is to detect any possible correlation between patients' understanding of the diagnosis, their level of engagement, and their compliance. We audio-recorded 32 visits of diagnosis with the oncologist or the surgeon or the gastroenterologist; at the end of the visit, we gave to the patients the Patient-Health Engagement Scale (PHE-Scale®) to be filled. Within three days from the visit, we interviewed the patients about their experience of communication during the diagnostic visit; during the interview, we also collected biographical data. We transcribed and then analyzed the visits using the Misunderstanding Codebook (Rossi&Macagno 2019). Eventually, we checked patients' compliance from their medical record. With the results obtained from the qualitative analysis, we also performed statistical analysis. The pilot shows interesting characteristics of the interaction at this sensitive moment; among others: physicians' attitude to talk a lot about the diagnosis without naming it; patients' tendency to ask questions about treatments; possible correlation between patients' age and their level of (mis)understanding; apparently, patients are not aware of experienced misunderstandings; patients' phenomenon of masking; possible correlation between level of engagement and level of education. The quali-quantitative methodology used in this pilot study is original and revealed itself to be useful and fundamental to find out the results we were looking for. The next step is to conduct the same study with a bigger sample; this may finally lead to useful guidelines to approach a sensitive moment like the one in which the professional has to convey information about a severe diagnosis to the patients and their families.

Can empirical bioethics be descriptive?
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Bioethics has traditionally been a purely theoretical discipline. Addressing moral issues and ethical dilemmas in biomedicine requires a certain degree of interdisciplinarity. However, since the 1970s the bridge between biomedicine and moral values has been mostly built using the

tools offered by theoretical disciplines, be they theology, moral philosophy or legal scholarship. Interdisciplinary work has mostly been confined to theoretical disciplines. Philosophers could work with lawyers to address ethical issues posed by medics. Yet, they both did not engage well with social scientists. The past couple of decades have seen an increasing interest among bioethicists in introducing empirical research methods in bioethics. Empirical bioethics aims to employ research methods developed within the social sciences in order to address ethical issues in biomedicine. It aims to engage social actors in real-word settings in order to investigate moral issues and ethical dilemmas that arise from technological innovation and social changes in biomedicine. In translating research methods from the social sciences into bioethics, empirical bioethicists have been concerned with two methodological issues: Can we combine facts and values, descriptive and normative? And if so, how do we combine them? What methodologies should we develop in order to combine descriptive and normative in empirical bioethics?
In this talk, I ask the question: can empirical bioethics be descriptive? Is there room for descriptive research within empirical bioethics? Must all bioethics reach normative conclusions? While they develop strategies to answer the (fundamental!) question of how to combine facts and values or descriptive and normative in empirical bioethics, bioethicists risk overlooking the fact that much social research does not aim to answer normative questions. While some social research does address normative questions, much social research aims to describe social phenomena and to interpret them in light of existing theories or in light of theories that are inductively developed from research data. Qualitative researchers, for instance, most often do not aim to reach normative conclusions; they wish to describe and interpret social actors' views, understandings, and conceptualizations. Qualitative researchers quite often wish to describe and interpret the social world, not argue how it ought to be. Can descriptive ethics play a legitimate role within empirical bioethics? In this talk, I argue that it can. I present some theoretical avenues as to why descriptive social science research can be an integral part of bioethics without necessarily having to produce normative statements.

Preferences of older Americans for length of life after a diagnosis of dementia

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We know little about how currently competent people value their continued lives should they become demented. The goal of the study is to understand the opinions of people over 50 with regard to 1- how long they would hope for their lives to go before experiencing a fatal event; 2- if and when they would refuse life-sustaining medical care should they become demented.
The survey presents a series of vignettes that outline the stages of Alzheimer as told via the story of a fictional patient. Qualtrix was used to complete a survey of 1,000 participants.
56% of participants responded that they would wish to experience a fatal heart attack in the very first stage of Alzheimer; 20% chose the second stage, still living at home but unable to drive and exhibiting increasing erratic behavior. 20% would wish their families to refuse antibiotics if they got pneumonia while in the first stage, and 35% at stage two.
This problematizes certain medical decisions, e.g., whether to give cholinesterase inhibitors to people with Alzheimer, as it addresses some symptoms but decreases risk of heart attack; and whether and when to enroll people with dementia in cancer trials. How would practice and policies change if we could acknowledge and respect this diversity of opinion with respect to lifespan after a diagnosis of impending dementia?

Bodily integrity versus family interests

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In this talk, I look at tensions that may arise between respecting individuals' bodily integrity and respecting familial requests. I start by briefly reviewing four different kinds of cases: reproduction with a dying or deceased spouse, use in reproduction of reproductive material from one's deceased offspring, fertility preservation for children, and uterus transplants from mother to daughter. Such cases are not hypothetical or exceptional. Spouses have requested – and obtained – collection of reproductive material from their unconscious or deceased partners and have used it in reproduction. Parents have requested – and obtained – access to their deceased children's gametes or embryos and used them in order to produce grandchildren. Children have undergone invasive experimental surgery to collect and preserve reproductive material for future use, at the behest of their parents. Most cases of uterus transplants to date have been performed from mother to daughter: but not all mothers who have been asked to donate have agreed to part with their uterus.
I use these cases to tease out the interests that may be at play in the request – and success – of such endeavours. To date, much the ethics literature on posthumous reproduction and fertility preservation for children has sought to justify intervention in the name of the interests of the person being harvested, or in the name of familial interests (which are assumed to include and express the interests of the person to be intervened on). I problematise these claims and contrast them with the demands of bodily integrity – which are only compounded by the fact that an individual may be unable to or very much expected to consent. I explore the claims that are made in such cases with a focus on purported surviving or future reproductive interests and the interplay between the interests of family members as well as the role of the family in determining whether medical interventions are justified.

The difficult birth of empirical digital bioethics

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A growing trend in bioethics highlights the importance of using big data science methods to support normative arguments. This is also called the 'digital turn' in bioethics. Automated data processing can, for example, detect significant patterns of correlation that have escaped the attention of the human bioethicist so far or machine learning algorithms could be trained to guide ethical decision-making about the fair allocation of scarce resources in medicine. Although we support the idea that such technological innovations could bolster existing methods in empirical bioethics, we argue that it should not be conceptualized as a new turn but rather as a reanimation, and possible magnification of entrenched debates in empirical bioethics. First, we compare the evolution of empirical bioethics with this recently launched 'digital turn' and indicate that is deceptive to speak of a new research field for the latter. In the second part, we focus on the fundamental challenge of integrating empirical research with ethical arguments. For this we draw on insights taken from the debate on setting normative standards for empirical bioethics research. For instance, principlism and its related bridging methodology of reflective equilibrium (RE) is often mentioned as a potential candidate to be programmed and digitalized. However, the existing empirical bioethics' literature has already indicated that bridging methods based on RE are fraught with conceptual challenges as explicit uses of it are difficult to locate. Moreover, there are other types of bridging methods, such as dialogical methods that escape the scope of algorithms to a considerable extent. Finally, we highlight that after the

initial digital hype tempers, searching for the right methodological tools in empirical bioethics is still work in progress and further debates on the sources of morality should not be shunned.

On the normative validity of decision quality instruments in medicine

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Patient decision aids (PDAs) are increasingly used in medicine. Whether patient brochures or web-based tools, all are meant to support patients in making better decisions about their care. However, many different outcome measures are used in effectiveness research on PDAs, thereby determining what a good decision should look like. One such outcome measure is decision quality. In my previous work, I investigated the relationship between Decision Quality Instruments (DQIs) and patient autonomy. In this talk I reflect on the methodological aspects of this work by asking which role normative knowledge (i.c. theories of autonomy) should play during the psychometrical validation of assessment tools (i.c. DQIs). Anna Alexandrova's (2017) work in philosophy of science on values and psychometric validation and her concept of normative validity will guide this reflection.

Psychometric validation is coherentist in spirit. An assessment tool (i.c. DQI) is shown to be valid if it respects relevant background knowledge. The term "normative validity" was coined by Alexandrova and Haybron (2016, 1099) and emphasizes the normative dimension of psychometric validation. That is, it highlights the fact that relevant background knowledge might encompass normative knowledge (i.c. theories of autonomy). In this talk, I will investigate how theories of autonomy are relevant to both content and predictive validity.

Content validity requires that all and only items relevant to decision quality are included in DQIs. Theories of relational autonomy cast doubt on the content validity of DQIs. To illustrate this, we need to look at one specific part of DQIs that assesses the fit between patients' choices and their values (i.e. the concordance part). Content validity raises the question which values should be taken into account in the concordance part. The literature on relational autonomy suggests that people might be better in articulating what is important to them in dialogue with their loved ones. In light of this literature, then, it is striking that patients are asked individually what items are most important to them during the development of DQIs. This seems to amount to a double standard for clinical decision-making versus tools that evaluate clinical decision-making such as DQIs and relates to what Alexandrova (2017, 141) calls "conversational subjectivism".

Predictive validity requires that concordant decisions result in less regret and more confidence than non-concordant decisions (Sepucha et al. 2012, 5). Looking back on their decisions, patients who receive treatments that match their values are expected to experience less regret and be more confident that their decision was right, than people who received non-concordant care. These links between the quality of decisions, regret and confidence can be questioned. I will relate this to a general concern voiced by Alexandrova and Haybron (2016, 1107) called "correlation mongering."

The foregoing examples indicate that normative knowledge (i.c. theories of autonomy) is relevant to, and sometimes in tension with, methodological choices made during the psychometrical validation of assessment tools (i.c. DQIs). This is highly relevant as it would make little sense to evaluate decisions using assessment tools that do not align with our normative knowledge.

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The Social Epistemology of COVID-19 (Un)Truths and the Bioethical Imperative for Democratizing scientific knowledge.

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The destruction wrought by COVID-19 has elucidated two underappreciated areas of bioethical inquiry relevant to human survival/flourishing. The first is the urgent need for a vigorous recommitment to global bioethics concerning global problems such as pandemics. The second area is the foundational imperative of democratizing scientific knowledge as evidenced by the disjointed responses to COVID-19 across the globe. This analysis seeks to relate the two areas as well as provide evidence and analysis to buttress their importance/centrality to the current global conundrum.

Beginning with the disparate understandings of COVID-19 it is clear that not only is scientific literacy clearly lacking among many persons but there is significant siloing of COVID-19 knowledge based on profession and intention. In the political bureaucratic areas, especially national and state governments, it is evident that the priority was and is national security and perhaps simply nationalism. This unfortunate truth is borne out in the myriad of ways national governments engaged in resource/information hoarding, xenophobia, and utter medical brinkmanship. These nationalistic incentives drove many political actors/states to interfere with and misrepresent evolving scientific data, examples include China's secrecy and opacity in information sharing and scientific contribution.

Another example is the initial refutation of mask-efficacy by American public health officials due to longstanding supply-chain inadequacies, causing mass confusion and distrust amongst the public. These unholy incentives also are evidenced in the public health authorities' shameful decimation of government mandated quarantine guidelines not based in immunology but based in crude economics and the support of a societal system devoid of social safety nets. This is not to besmirch the reputation of individual politicians or scientists but to point to larger systemic and institutional failures. These uncomfortable truths lead many laypersons who did not exist in the social epistemic circles of professional politics or science to form their own circles of understanding and be enveloped into contrarian sophistry. The main source for this deception was the creation of non-critical social-epistemic circles on social media partially formed by algorithms intended to maximize engagement and consequently ad-revenue. Because laypersons arguably far outnumber professional specialists and policymakers, the damage is tremendous.

Several American universities, which produce many of the specialists, aligned their institutional policies with the political economic imperative of 'returning to normal' due to their own bottom

lines. Like so many other workplaces, the academy insisted on in-person instruction despite the obvious risks evidenced by their own researchers. These disingenuous interpretations are not universal. However, there were many citizens that followed more sound courses of action as there were also scientists and policymakers that have remained ever-vigilant and unwavering in the fight against COVID-19. The problem is, however, the disjunction in these responses only seeks to proliferate COVID-19 and its many variants. This analysis seeks to use these real world, real-time incongruencies to advocate for both broad and accessible dissemination of scientific knowledge. While social epistemic circles can be informative and positive, the scope of an effective circle for a pandemic is global.

Euthanasia in Belgium and the idea of suffering: from fate to choice

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Since 2002, Belgium has a legislation on euthanasia. In 2014, it became the first country in the world to allow euthanasia for those under the age of 18. Though quite liberal, the law still precludes quit strict conditions to decide on euthanasia:

- the patient must be mentally competent to make the decision;
- the patient must request euthanasia on two separate occasions, in writing;
- the patient must be suffering from the effects of an incurable disease or mental illness, and all treatment options must have been exhausted;
- the patient must be experiencing unbearable suffering from the illness, either physically or psychologically.

One of the keystones of the law is of course “unbearable suffering”. It means that the law starts from the subjectivity of the patient regarding its situation, albeit that every euthanasia has to be linked to a medical situation. Nevertheless, the idea underneath the legislation on euthanasia in Belgium is to consider suffering is meaningless. It literally has no meaning anymore. It is important to notice that only because suffering has become meaningless for many people, since there is no longer any prospect of a reward after death, the legitimacy ground for earthly misery disappears. Enduring misery no longer fits within the idea of the good life. That is why the question of a good death - the literal meaning of euthanasia - is one of the ethical issues of our time.
In my talk, I will sketch some keystones of the law on euthanasia in Belgium, to go on with the topic of suffering and the shift from fate to choice when it comes down to end-of-life. Finally, I will discuss what French philosopher Paul Ricoeur writes in *La souffrance n'est pas la douleur*, that, unlike pain, suffering often has no identifiable object. Those who fall are in pain, and they suffer. But whoever has no perspective in life, suffers and asks: why do I have to go through this? In doing so, Ricoeur puts his finger on the wound in the end-of-life debate: does suffering have meaning at all?

“He does not have the right to destroy John’s data; therefore, he is not John.” An experimental bioethical study on the sameness of persons and the ascription of rights

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Given that diachronic identity “is a necessary criterion of most interesting diachronic legal relations” (Tobia, 2022), it is natural that bioethical debates on rights “at the margins of life” (from embryonic research and abortion to advance directives and assisted suicide) are tightly

interwoven with the philosophical discussions on personal identity. The dominant inference line in such arguments is that to settle normative bioethical questions about rights, metaphysical issues of identity must be settled first.
One recurring finding in empirical research on personal identity, however, is that ascriptions of personal identity seem to be sensitive to normative considerations. Someone who undergoes an abrupt change to their moral character is seen as transforming into a new person (Strohminger & Nichols, 2014, 2015, Prinz & Nichols, 2016; Gomez-Lavin & Prinz, 2019). This phenomenon was dubbed the essential moral self. Furthermore, such identity judgments depend on the direction of change. Moral deterioration is seen to be more disruptive to identity than moral improvement. This effect is called the Phineas Gage effect (Tobia, 2015; 2016; Earp et al., 2019).
I present four studies with lay and lawyer participants (total N = 3779), suggesting that there is a legal concept of sameness of person that, compared to the lay concept, is less susceptible to moral considerations and more tightly linked to rights. Lawyers seem to differ from lay participants in that their concept of sameness of persons is more insulated from moral concerns, both in being more immune to the change in moral character and less sensitive to the direction of such change. Furthermore, lay participants sometimes use ascriptions and denials of personal identity strategically (e.g., to justify denying rights to a morally flawed character). However, it is possible to make lay participants think about personal identity more like lawyers do by putting them into a legal frame of mind.

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Impartiality or closeness? On relationships in the treatment process.

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The psychology literature and the sociology of medicine points to the positive impact of closeness on the healing process. The importance of the family relationship in which the patient remains is emphasized. In the literature, different models of behavior, including communication in the relationship between doctor and patient, clash. Some of them assume the impartiality of the doctor; others that the doctor, in order to build trust in the relationship with the patient, must establish a closer relationship with him.

On the ground of law, for example, it is indicated that a judge is to be impartial - only then he will be able to correctly and objectively assess the case that has been presented to him for decision. On the ground of law, no such requirement is indicated for a doctor - he is supposed to act in accordance with his knowledge. However, his personal characteristics can affect how the treatment process will be carried out, how he will communicate his decisions. This raises the question of how professionalism in the practice of the medical profession is understood - as impartiality towards the patient or otherwise.
The relationship between doctor and patient is the most basic. Nevertheless, in some situations (terminally ill patients, unconscious patients) the doctor establishes a relationship with third parties to the patient. This raises the question of whether he should treat these people, analogously - as a patient or differently?
In my preliminary research, I assumed that a relational "triangle" may be formed in the process of treatment. I assume that the relationships listed below can interact with each other, affecting the final outcome of the treatment process. In the planned research, I would like to analyze the following pairs of relationships from a legal and ethical perspective:

1. the relationship between doctor and patient;
2. the relationship between the patient and third parties (some of which can be called close);
3. the relationship between third parties and the doctor.

In my presentation, I would like to determine how legal and ethical regulations shape the indicated relationships: to what extent do they regulate them at all, and do they indicate in which situations they should be close and in which situations they should be neutral (impartial)? In making these determinations, I will draw on psychological and sociological perspectives.
On the basis of the findings, I would like to formulate proposals for normative models of the above-mentioned relations and consider the possibilities of their practical application.

Intertwining moral philosophical analysis and discourse analysis in an empirically enriched reflective equilibrium - A three-step procedure for the investigation of public bioethics discourses

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The digitalization of health care evokes controversial public discourses that negotiate contested moral and political questions of medicine and healthcare. In this context, various bioethical concepts and narratives are employed in heterogeneous ways. A prominent example in the German-speaking area is the public discourse on self-tracking technologies in healthcare. Here, especially the concept of solidarity functions as a prominent but controversial normative reference point. However, while such discourses seem intuitively relevant for bioethics, it remains unclear what exactly constitutes this bioethical relevance and how these public discourses can be examined.
The goal of my contribution is to elaborate the bioethical relevance of public discourses and to introduce a procedure for their ethical analysis. A study of the public leading media discourse on self-tracking-technologies in healthcare in Germany will serve as an example. I first provide a short introduction to the public discourse on self-tracking technologies in healthcare in Germany and clarify the twofold bioethical relevance of this discourse: On the one hand, the heterogeneous, occasionally illegitimate application and the normative effect of ethical concepts can be traced in these discourses; to point out, make explicit, and evaluate these ethical concepts and narratives can be understood as a basic ethical concern. On the other, such discourses also shape and influence individual and political decisions in medicine and healthcare and, thus, have a practical relevance for the concrete subject area of bioethics.

I then sketch a three-step procedure for an ethical analysis of such public discourses. In a first step, a *moral-philosophical analysis* serves to develop a heuristic framework for identifying ethical concepts and relevant narratives as well as an ethical framework for evaluating them. The second is a *discourse analysis* which applies the heuristic framework to a specific public discourse to identify different notions and uses of the investigated concept. In the third step, these different notions are *ethically evaluated* and correlated within the framework of an *empirically enriched reflective equilibrium*. I illustrate the procedural steps and their interdependence with examples from the German public discourse on self-tracking technologies in health care. Thus, also for this discourse, with the help of the empirically enriched reflective equilibrium, it is possible to distinguish legitimate and illegitimate recourses to the concept of solidarity in the context of self-tracking-technologies in healthcare. The resulting spectrum of moral-philosophically legitimate and application-oriented uses of the concept can contribute to the shaping of a solidary *and* digital healthcare system.
Contrary to the criticism of philosophy's obliviousness of methods, I conclude that the empirically enriched reflective equilibrium offers the possibility to intertwine moral-philosophical analysis and discourse analysis and thus to expand and sharpen the methodological repertoire of empirically informed ethics.

Against claims of a/symmetry: The disunity of conscientious objection and provision.
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A number of contributions to the recent literature on conscientious objection have sought to articulate, advance and engage with the idea that respect for individual moral conscience should not only license refusal but also provision. Whilst not all accept the proposal, the suggestion is that there is a problematic asymmetry (Fritz 2021) in the way we respond to those who moral object to providing a particular service and those who moral object to not being able to do so. Thus, in contexts where it is legal for individuals to terminate a pregnancy, healthcare professionals who consider abortion morally wrong have their views accommodated; they can opt out of provision on the basis of their conscience. However, in contexts where termination of pregnancy is legally prohibited, parallel accommodations are not extended to healthcare professionals who consider non-provision morally wrong; they cannot opt into provision on the basis of their conscience.
This paper will consider whether this so-called asymmetry should be considered a problem for conscientious objection or if it demonstrates a problem with the way we—bioethicists—have understood conscientious objection. I argue that there has been a tendency to over abstract the notion of conscientious objection in healthcare; it is framed as a moral stance undertaken by individuals, when should be seen as a political compromise, meaning it is both collectively agreed and more issue specific than is ordinarily recognised. This alternative understanding sheds new light on the issue of conscientious provision and whilst both provision and objection should be understood as ethico-political undertakings, conscientious provision is more appropriately compared to civil disobedience, protest and resistance than it is to conscientious objection. Viewed in this way we can better understand some current responses to the situation in the USA, such as those proposed by Giubilini et al (2023), and elsewhere, including those that occurred in the past.

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From 1st to 3rd person perspective: Linguistic features in interviews with patients with chronic inflammatory bowel diseases in the context of emerging 'precision medicine'

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Background. The therapy of inflammatory bowel disease (IBD) often resembles a process of trial and error. Drugs such as biologics can lead to positive effects for some patients, while causing negative side effects for others. To address this problem researchers are currently developing precision medicine for chronic inflammatory diseases. Their goal is to classify patients based on their genetic, lifestyle and environmental data, in order to find personal traits on the basis of which a more tailored and in this sense a more precise therapy can be developed. Based on the premise that a therapy is only good if it improves the lives of patients, we are investigating the patients' body experience and the impact of self-tracking with wearables and health apps on patients' lives. Our results will serve to develop new and refine existing patient-reported outcomes.

Methods. Since Interpretative Phenomenological Analysis (IPA) (Smith & Nizza, 2022) is an appropriate method to study the lived experience of patients, we chose this method for the analysis of our qualitative interviews. According to this method, exploratory (descriptive, linguistic and conceptual) notes, experiential statements and experiential themes were formulated for each of the 10 cases studied. The investigation of linguistic features was particularly informative to understand patients´ suffering, as they often hide meanings that need to be deciphered first.

Results. For our analysis of the body experience of patients, the change from the 1st person to 3rd person perspective, the expressive language and the metaphors were especially meaningful. Patients used metaphors to describe their vulnerability and the (side) effects of drugs. Expressive language, with words such as "horror" or "the worst" were used to express fatigue and shame associated with the illness, but also the difficulty to get access to specialized care. Shifting from 1st to 3rd person perspective occurred frequently to distance oneself from the condition. Either the body itself or the disease was more often described as a second subject, as a cohabitant in one's own body with whom one has to reconcile, and one person even gave this subject a first name.

Discussion. In the broader context of a “phenomenologically informed hermeneutic approach to bioethics” (Rehmann-Sutter, Porz, & Scully, 2012) we appreciate the study of linguistic features with IPA as particularly valuable when the knowledge of the "lived experience" can enrich the answering of normative questions. In our study, understanding life with IBD serves as a starting point for the reflection on how precision medicine can alleviate patient suffering, which some authors have identified as the most important ethical principle in medicine (Svenaeus, 2018).

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Shifty Work Around Shift Work: Novel Critiques of Enhancement

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Debates over performance enhancement are ubiquitous in medical ethics, but are often tied to extreme changes in capacity by supposedly healthy actors. This framing rests, however, on key distinctions between enhancement and therapy that assume certain political, ideological, and social background conditions about desirable bodily norms, and what constitutes disability or ill health. In this paper, we take the phenomena of shift work sleep disorder as our starting point. This is a diagnosis given to individuals whose circadian rhythms are disrupted by their work schedules. It is a common indication for the prescription of modafinil, the wakefulness-promoting poster child of the enhancement movement. We argue that the diagnostic category of shift work disorder is mobilized to blur the lines between therapy and enhancement in ways that permit pharmacological treatment of a bodily state that arises through labor conditions. This reveals how the treatment-enhancement distinction is not merely a conceptually fuzzy boundary, but also a boundary that is negotiated as part of various political and social maneuvers. It moreover underscores how the administration of US American medicine is inextricable from the country's approaches to health, welfare, and resourcing of social goods. Following from this, we develop a novel critique of enhancement, located in the way that capacity, disability, and enhancement interact with the incentive structures of liberal, capitalist democracies. In particular, we explore how in US American contexts, the category of disability is rooted in judgements about capacity, which are often judgements of capacity to work. This has profound implications for what kinds of interventions insurance (which is generally accessible through one's employer) will cover, as well as the kinds of social safety network supports that are and are not made available for those diagnosed with disabling conditions. In so doing, we link questions of ability to questions of enhancement to norms around capitalism, which undergird the very possibility of a diagnosis of shift work disorder. We then turn to other examples in which boundary work between treatment and enhancement; disability and the ability to work; and medically necessary and elective interventions are deployed to condition the relationships possible between bodies, health, and what it means to work. We conclude with a sketch of how changes to welfare models between states—whether between e.g. the liberal US and social democratic Nordic countries; or between instantiations of the liberal state in the US, UK, and Australia—might change what constitutes an enhancement, and why.

Research Ethics and Enhancements: What Are Appropriate Clinical Endpoints?

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Human enhancement is a perennial and arguably foundational topic in biomedical ethics, and has received considerable attention from philosophers. However, the vast majority of this work has focused on what can be described as "end-use" questions: should be become enhanced; does enhancement alter human nature; what are the individual and social limits on

enhancement? Very little has described enhancement research as a distinct process, and those that do often assume that enhancements work much like therapies.
In this paper, I challenge this idea and provide a path forward to develop enhancements broadly considered—physical, moral, cognitive, and so on—as a research enterprise. Drawing on a literature review of the clinical literature of performance enhancement research with a focus on enhancements, I examine three wakefulness drugs: modafinil; amphetamines; and caffeine. I argue that a) what is good for the therapeutic goose is not always what is good for the therapeutic gander, i.e. that enhancements are not simply therapies applied straightforwardly to healthy individuals; b) that even well studied enhancements often struggle from a lack of appropriate effect size and clinical endpoints; and thus c) that developing a clinically robust enhancement research protocol is not straightforward. I then show how we might better structure enhancement research in minimal risk contexts, and then in riskier contexts moving forward.

Why baseline theories fall short in assessing the coerciveness of kidney markets
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The shortage of kidneys for transplantation has led to a contested debate over whether or not a regulated market for kidney sales should be allowed. One argument raised against allowing such a market is the argument from coercion. Although often conflated, one line of this argument focuses on coercion through poverty itself while another formulation focuses on the coerciveness of irresistible offers. The focus of this paper will be the latter. In line with baseline theories of coercion, opponents of the argument from coercion hold that offers cannot coerce. Offers are held not to be coercive because they provide recipients with an additional option, they do not have to accept without rendering any prior option ineligible. Recipients will, therefore, commonly welcome the offer, that is, they will be willing to be moved from the pre- to the post-offer situation. Drawing on Rippon (2014), I will show that this justification does not hold in the case of allowing for a legal kidney market and baseline theories, therefore, fall short of proving kidney markets would not be coercive. I will argue that this is because they fail to take into account the structural consequences the introduction of the market would cause.

Intersectionality in clinical bioethics – suggestions for discrimination – critical clinical ethics consultations
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Bioethics increasingly recognizes the impact of discriminatory practices based on social categories such as race, gender, sexual orientation, or ability, on clinical practice. In line, major bioethics associations have stressed that identifying and countering structural discrimination in clinical ethics consultations (CEC) is a professional obligation of clinical ethics consultants. Yet, it is still unclear how clinical ethicists can fulfill this obligation. More specifically, clinical ethics is in need of both theoretical tools to analyze structural discrimination and practical strategies to address it within CEC. Intersectionality, a concept developed in Black feminist scholarship, is increasingly considered in bioethical theory. It stresses how social structures and practices determine social positions of privilege and disadvantage in multiple, mutually co-constitutive systems of oppression. In this presentation, I argue that intersectionality may

contribute to discrimination-critical CEC in three ways: as an epistemic stance, as a theory checker and as a transformative praxis.
First, I suggest intersectionality to be used as an epistemic stance within CEC to frame the ethical conflict. Intersectionality pays attention to the influence of structural discrimination on clinical practices and associated ethical conflicts that may otherwise remain unrecognized. Taking an intersectional epistemic stance means explicitly considering the role of discriminatory practices and structural power relations that may contribute to an ethical conflict – for example during the collection of relevant (medical, social, legal and personal) facts that forms the beginning of each CEC. This allows for a more in-depth understanding of the ethical problem at hand. Clinical ethicists can acquire the necessary intersectional sensitivity through trainings, such as the structural competency training.
Second, intersectionality may inform CEC as a theory checker. Clinical ethics practices have been criticized for prioritizing theories and norms which are based on Western approaches to ethics, health and disease, and which are shaped by dominant social practices and conventions. If such approaches are adopted within CEC without further reflection, this might marginalize patients' values and preferences and undermine finding a consensus in the CEC. Using intersectionality as a theory checker means explicitly discussing the chosen ethical approach as well as biases in values and background assumptions. On a theoretical level, bioethics needs to invest more research into broadening the ethical approaches and integrating knowledge from intersectional scholarship into established ethical principles. Further, diverse compositions of clinical ethics committees can support a broader variety of perspectives and may thus reduce bias in background assumptions.
Third, intersectionality may inform CEC as a transformative praxis. Intersectionality recognizes how power structures shape clinical encounters. It thus helps to understand practices of silencing within CECs, which may operate via stereotypes, prejudice, and microaggressions. Applying intersectionality as a transformative praxis within CEC means that clinical ethicists take the role of patient advocates and use their mediation and conflict resolution skills to facilitate an open and discrimination-critical discussions. Preconditions are explicit institutional support for anti-discrimination efforts, as shown through public statements and concrete measures, such as staff training, implementation of complaint structures or disciplinary procedures.

How Philosophy of Science Can Unlock New Methods in Bioethics
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Philosophy of science has historically been concerned with scientific methodology. These efforts to understand scientific methods have always been inherently normative: the methods of scientific inquiry are what scientists should do. But these efforts face an important constraint: accounts of scientific methodology that are incompatible with the nature of scientific expertise are methodologies that can make no difference to practice.
It is not widely understood that an analogous constraint applies to bioethics. Both philosophy of science and bioethics are inherently normative. But beyond this, since clinicians are users of technical, specialized knowledge, the ethics of clinical practice must be compatible with the nature of clinical expertise if it is to make a difference to practice.
How can we ensure that bioethics respects this constraint? Since philosophers of science have generated reasonably accurate accounts of various scientific methods, we can assume that these accounts are generally compatible with the nature of scientific expertise. The same compatibility may therefore accrue to bioethics if the field pursues avenues of inquiry that start

from assumptions that are independently plausible given the best available philosophy of science.
The core of my proposed paper, then, is to introduce three such assumptions.
To wit: Clinical Care as Constructing and Updating Models: Diagnosing and treating a patient is a dynamic process in which teams of clinicians collaborate in the construction and revision of a model of the patient's illness. By assuming that the "epistemic object" that skilled clinicians are working with is a model, bioethicists can partner with clinicians in the construction of the model, and thereby influence the ethics of the care through directing changes to this model.
Methodologies, Not Principles: Rather than developing arguments for, or which are based upon, principles, bioethicists could develop methodologies. What is the difference? Principles are general across targets of intervention, conceptually abstract, and invariant. Methodologies are specific to some target of intervention, conceptually concrete, and dynamic. An ethical methodology might therefore be guidance about how, in some particular healthcare institution, or when working with a specific clinical speciality, the ethical quality of a model of a patient's illness can be improved.
Social, Not Individualistic: Both traditional bioethics and foundational ethical training for clinicians assume that the mechanisms by which clinical ethics is implemented is through a commitment on the part of individuals to a set of general ethical principles — or if not that, then to a professional code of ethics. An alternative grounded in philosophy of science explores how clinical ethics can and should emerge from complex social interactions between individuals, clinical processes, and institutions. It assumes that ethics is about the structure of groups of clinicians cooperating together to provide care, and that individual beliefs are a consequence, not a cause, of this structure.
Developing new lines of inquiry in bioethics starting from these assumptions would represent a methodological break from many traditional approaches in bioethics. The value, again, is that doing so would provide a reason to believe that bioethics is compatible with the nature of clinical expertise.

Are (some) enhancements (sometimes) less controversial than (some) treatments (in some ways) for (some) persons with (some) disabilities?
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The 1982 Splicing life Report on the social & ethical issues of human genetic engineering emphasised two now famous distinctions: between somatic and germline genome editing in humans, and between medical treatment and non-medical enhancement. In the forty years since, these distinctions have highlighted significant differences in the moral appraisal of potential genetic engineering technologies and their potential applications. The recent WHO Framework document (2021) notes how, in context of the future possibilities of both somatic and heritable interventions, that good governance needs to explicitly evaluate the (im)permissibility of the use of human genome editing technologies for enhancement purposes. In this presentation, I wish to focus on how the existence of the treatment/enhancement distinction seems to have created a reasonably stable division between a concern for persons with disabilities and concerns about the potential for human genetic enhancement. And in doing so, I think this has led to a skewing and undue narrowing of ethical discussions and positions one can take.
Usually enhancement is considered more controversial, and the image of treatment as less or even uncontroversial. However, for persons with disabilities, it is far from clear that the image of 'treatment' is any better, or less of a threat, than the image of 'enhancement'. In many/all ways, we are all suffering various impairments, but under the moral image of treatment, some

are grouped under so-called normal ranges and others outside of this. On the other hand, while the concept of therapy may isolate some persons from others, enhancement puts us all in the same (unenhanced) boat. This is a gross oversimplification but perhaps highlights that there may be a plausible case for speculating that the 'less controversial treatment' versus 'more controversial enhancement' discussions are importantly ignoring an interesting diversity of views. For instance, whether it would be perfectly reasonable for a person with disabilities to desire enhancements but not treatments. How many persons would share such a "pro-enhancement but anti-treatment view" is an empirical question. The question I merely raise is whether this is a coherent position to take and whether it might be productive for decreasing some polarisation arising between long standing divergent perspectives.

Shiny new toys: Knowledge structures and (in)equity in access to molecular technologies

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Advances in molecular technologies have the potential to help remedy health inequities through earlier detection and prevention; if, however, their delivery and uptake (and therefore any benefits associated with such testing) are not more carefully considered, there is a very real risk that existing inequities in access and use will be further exacerbated. We argue this risk relates to the way that information and knowledge about the technology is both acquired and shared, or not, between health practitioners and their patients.

Our work falls under the umbrella of Fricker's notion that harm can be done to another person in their capacity as a knower. When someone is not perceived as having the capacity to understand information by another, this affects how, what, and if information is shared between them – in other words, they experience informational prejudice. We take the position that both practitioners and patients are vulnerable to epistemic injustice (and thus experience informational prejudice) owing to prevalent negative stereotypes and certain structural features of contemporary healthcare practice. Our journey to this position comes from our experiences in our respective fields of indigenous and health research, epistemology and medical sociology – where, in reference to new molecular technology, we have frequently heard comments such as "oh well they won't understand" or "I don't have time to explain it to them". Where the they and them can be in reference to either and/or both 'certain' practitioners and patients. Such biases and position are bound to have an impact on meeting our health care ideal of enabling people to make an informed choice in their decision to undergo testing or not.

A health care system can be viewed as a complex social network comprising individuals with different worldviews, hierarchies, professional cultures and sub-cultures and personal beliefs, both for those giving and receiving care. When health care practitioners are not perceived as knowledge equals, they would experience informational prejudices, and the result is that knowledge dissemination across and between them would be impeded. The uptake and delivery of a new technology may be inequitable as a result. Patients would also experience informational prejudice when they are viewed as not being able to understand the information that is presented to them, and information may be withheld.

Informational prejudices driven by social relations and structures have thus far been underexplored in considering (in)equitable implementation and uptake of new molecular technologies. Every healthcare interaction represents an opportunity for experiencing informational prejudice, and with it the risk of being inappropriately informed for undertaking (or offering) such screening or testing. Making knowledge acquisition and information dissemination, and experiences of informational prejudice, explicit through sociologically

framed investigations would extend our understandings of (in)equity; and, offer ways to affect network relationships and structures that support equity in delivery and uptake of these shiny new toys.

The Primacy of Phenomenological Perspectives in Medicine

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The focus on empirical data rightly underpins the field of medicine and constitutes the fundamental approach to differential diagnosis. The dependence upon such an approach goes without saying, as quantitative evidence is both statistically dependable and logically deployable. However, some medical consultations involve both quantitative and qualitative evidence. When such consultations occur, the qualitative evidence is often 'overwritten' and the phenomenological 'lived-experience' is ignored because it doesn't fit with the analysis of situation as received by the medical professional — that is to say, some doctors ignore or diminish the lived-experience because they don't believe that they properly inform the clinician or are not in the patient's best interests.

The resultant difference of opinion is often interpreted by the patient as 'steamrolling' or as a 'medicalisation' of their experiences, and sometimes perceived by the doctor as 'un-educated or irrelevant testimony'. The result is that the patient does not always end up with the treatment or intervention which best suits their lives and the doctor makes a decision which fails to take into account important information about the kind of quality of life (QOL) some given intervention will bring about. Such difficulties occur, for example, in the prescription of prosthetics for very young children (which has the result of diminishing the infant's ability to adapt naturally to the world in which they live); the prescription of pharmacological responses (rather than surgical interventions) whose side effects reduce a persons QOL; or in the preference for avoid the 'expensive' treatment in favour of repeated, but ineffective, less expensive interventions.

While the phenomenological perspective is statistically less indicative, deferring to bio-statistical 'norms' for persons who, in virtue of bodily or mental difference, are not 'bio-statistically norm' can be misleading and result in solutions which are less effective and reduce the quality of life of the individual. The question at the heart of this matter, therefore, is to what extent should the primacy of the lived experience be permitted to influence medical decision making and at what point should the clinician redoubt in the logical and statistical medical decision?

In this presentation I present several examples of where the phenomenological perspective has been 'trumped' by dominant medical thinking, demonstrate alternate resolutions to the medical experience, and consider the process by which clinicians are taught to defer to statistical evidence in preference to the lived-experience during medical school.

Mixed Signals: The integration of conceptual and empirical research to distinguish trustworthy behaviour from trustworthiness signalling in health data sharing practice

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Introduction. With the emergence of machine learning and artificial intelligence technologies, the use of patient data is a reality of healthcare today. In the UK, calls for public trust in health data-sharing practices are increasingly heard, with much emphasis being placed on the need for

trust in institutions that stand to profit financially from data access. Given the way in which healthcare research has become integrally linked with wealth creation, establishing trustworthy health data access when commercial interests are involved is crucial. However, if we are to do this, it is essential to be able to distinguish trustworthiness from trustworthiness signalling in this context.

Methods. This project uses empirical bioethics to make this distinction between trustworthy practice and trustworthy signals, and adopts the approach developed by Dunn et al (2012). As such, it will integrate normative theoretical and empirical components in an iterative way. This means that the conceptual philosophical component will run throughout the entirety of the project, continuously informing as well as being informed by the empirical work.

Using case study examples, this presentation will work through some key conceptual elements for trustworthiness in health data-sharing practices and then impose these elements on the empirical data collected during interviews with researchers working with health data in the UK. This exercise will identify the substantive nature of demonstrated trustworthiness in an effort to determine what contributes to genuine trustworthiness rather than that which merely signals trustworthiness in this context.

Conclusion. Given the performative nature of words like trust and trustworthiness, it is important to clearly define what is meant when using them in the health data context, and in particular when commercial interests are involved. These distinctions help to set expectations which are intrinsically placed alongside word choice, as well as highlight areas which need further clarification. Unpacking the difference between genuine trustworthiness and trustworthiness signalling will help to define what is needed from institutions accessing health data as we work toward building public trust in a data-driven future. In this case, empirical bioethics offers a justifiable standard from which to begin these complicated conversations.

Can Public Reason Yield Legitimacy and Justice in Bioethics?

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Can Rawls' conception of public reason resolve, or at least ameliorate, some of the more controversial ethical and policy issues in bioethics? We begin with a summary of Rawls' conception public reason. How can we live peacefully with one another when we, citizens in a liberal, pluralistic society, are committed to radically incommensurate comprehensive doctrines (moral, religious, political, ideological) from which we derive our preferred responses to ethical and policy issues in bioethics? This is Rawls' fundamental problem. He introduced the notion of public reason into our political environment as a perspective that all citizens as citizens could embrace for purposes of addressing rationally such controversial issues. For public reason to be effective, citizens as citizens must put aside their comprehensive doctrines and invoke only public reasons and public values that all can accept as reasonable and relevant to addressing prevailing ethical and policy controversies in bioethics today.

Next, for illustrative purposes regarding issues of justice and legitimacy, we use CAR T-cell therapy, population screening for cancer with the Galleri liquid biopsy test, and the allocation of ECMO slots when insufficient relative to need. The Galleri test would screen annually for more than 50 cancers at the earliest stages for $950, for 110 million individuals in the US over age 50, at a cost of more than $100 billion per year, claiming to reduce annual cancer deaths by 140,000 per year based on a statistical model. Is a just and caring society ethically obligated to underwrite this screening test from the perspective of public reason?

The first goal of public reason is to eliminate unreasonable options. In the case of our resource allocation challenges above, grossly inefficient uses of limited health care resources would be

unreasonable, as would the use of medical/ scientific misinformation to justify an option, including the violation of the publicity condition regarding health care justice. Also unreasonable would be an excessively restrictive option that could only be justified by appeal to a comprehensive religious or non-religious doctrine. Allocation options that failed the impartiality test (favoritism toward GRAIL/ Galleri or onco-exceptionalism) would also be unreasonable. Allocation options that were essentially illiberal, or that violated fundamental considerations of health care justice, or that failed to give due regard to other relevant fundamental social values would also be unreasonable.
In many cases, having pared away unreasonable options, we would still be left with several reasonable options. The second goal of public reason would be to construct a democratic deliberative process that was fair and inclusive, and that sought to identify among reasonable options that option that achieved a wide reflective equilibrium endorsed through the deliberative process. We conclude with responses to two major criticisms of the role of public reason in bioethics.

On methods of recovery for addiction: making space for emotions

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Emotions, especially painful[1] ones, have since long been considered as catalyzers to substance-use and abuse problems. For example, according to a well-known perspective first developed by Edward Khantzian, addiction can constitute a way to self-medicate oneself (Khantzian, 1985; 1997; Khantzian and Albanese, 2008). Indeed, the self-medication hypothesis (SMH) considers that addicted individuals use drugs in order to alleviate and soothe an uncomfortable affective state of being. The SMH has also been endorsed by psychotherapists, namely Beth Burgess (2016), who recognizes a truth in the saying "hurt people hurt people". For Burgess, most, if not all, addicted individuals hurt themselves by using because they have experienced great emotional pain in the past. Besides the SMH, there are researchers that defend the idea according to which certain unpleasant self-conscious emotions, like guilt and shame, should be avoided by addicted individuals in their recovery processes, as they can be very pernicious and cause relapses (Snoek et al., 2021). Blame, which can be defined as an affective state (Pickard, 2013), has also been tackled by philosophers in the purpose of showing that it is not useful nor appropriate in addiction recovery (Pickard, 2017; Brandenburg, 2018). Through these various attempts to characterize addiction in its relation to emotions, we may however wonder if it is always the case that such affective states play a role in maintaining addictive behaviors. In other words, we may ask if emotions, albeit painful or distressing ones, are always a disservice to addiction.
In this presentation, I wish to defend the view according to which some emotions typically classified as painful ones constitute a necessary step in the pathway to recovery. In particular, I would like to argue that self-shame and self-guilt, which are typically seen as very unpleasant emotions, most likely have to be felt, endured, and eventually surpassed in order for an addicted person to recover from his addiction. Such a conclusion is to be drawn as we take a look at addicted individuals' own accounts of their addictions, which often refer to recovery by way of surpassing (which is different from avoiding) these emotions (Snoek et al., 2021). I will however also agree with Pickard and Brandenburg that blame and self-blame are neither necessary nor desirable affective states for one to experience in addiction recovery.

[1] By painful emotions, I mean emotions that are distressing and unpleasant for the person experiencing them.

In arguing that some painful emotions are part of the recovery process, I do not wish to say that we should encourage addicted individuals to feel them more greatly. Rather, I mean to offer theoretical grounds to the practical goal of helping addicted individuals better handle these emotions. As a matter of fact, if addicted individuals in recovery cannot avoid self-guilt and self-shame, then, in the methods we use and implement in their recovery processes, we should emphasize their need to learn how to understand and manage their experience of these emotions.

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Normative Empirical Ethics

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Ethics is usually divided in normative ethics, descriptive ethics and metaethics. Methodological questions about ethics should qualify as metaethics. Empirical sociological research - often qualitative studies - about ethical questions are (mainly) descriptive. Normative ethics is about values and usually implies judgments about actions or moral demands on agents.
Moral as well as scientific theory have been eager to warn about meddling value judgments and empirical results, and one of the classical mistakes since David Hume is to conclude from “is” to “ought”. Thus, I intended the title of my abstract is as a little provocation. At the same time, it is a description about a method of doing ethics where the “is” and the “ought” inspire each other: though neither the “is” has normative power in itself, nor the theoretic “ought” is usually directly applicable to practice, the mutual provocation of theory and practice is immensely fruitful to both. Though they may not be logically in the same sphere, the ideal of a reflective equilibrium where practice and ethics coexist in a mutually informed balance may deserve the contradictive name “normative empirical ethics”.
Does this sound utopian and far from ethical research practice? I would like to present an example from psychiatry: the normative principle of autonomy meeting the reality of patients with emotionally instable personality syndrome with frequent and not very deliberately chosen self-harm. In my presentation, I will illustrate the crash between respect of the patient’s (frequently changing) will on the one side and the need of therapy and protection on the other, with an inevitable confrontation that risks harming the patient even more. The idea of “relational autonomy” opens a way out of the dilemma, and the therapeutic practice gives evidence of the effectivity of these thoughts. This inspires the conclusion that a strengthening

of the patient´s autonomy has a therapeutic effect, which gives a stronger position to the normative ideal of autonomy in clinical practice. The unholy alliance between norms and empirics (not to mistake for simple appliance) is therefore nothing we should avoid, but an important source of advance in both theory and practice.

Bioethics and the Question of Interdisciplinarity: Islamic Bioethical Discourse in Focus

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This presentation discusses interdisciplinarity, one of the key characteristics of modern bioethics. Collaboration between interdisciplinary fields has been central to the development of bioethics. However, interdisciplinarity outside the mainstream secular discourse remains understudied. Thus, this presentation will assess how Islamic bioethics compares or differs from secular bioethics in terms of interdisciplinarity.

The introductory section discusses interdisciplinarity in secular bioethics, with particular attention to the shifting roles of biomedical specialists and religious studies specialists. Section two analyses interdisciplinarity in Islamic bioethics, focusing on the same two disciplines. Finally, the presentation will propose ways to enhance transdisciplinary communication between secular and Islamic bioethics, including the role of institutions such as the European Society for Philosophy of Medicine and Healthcare (ESPMH) and the International Association of Bioethics (IAB).

1. Interdisciplinarity in secular bioethics. The field of bioethics is interdisciplinary by birth. Back in the 1960s and 1970s, it was introduced as a bridge-discipline between the two cultures of modern society, viz., the sciences and the humanities. Over time, interdisciplinarity became fundamental to bioethics. However, bioethicists still disagree on the list of disciplines to be involved and how the synthetic work can be done without sacrificing the disciplinary rigor (Potter, 1971, Iltis 2006; Ten Have 2012; Ten Have 2013).

At its beginning, the bioethical discourse was mainly shaped by specialists in the biomedical sciences and religious studies. Later, philosophers took over the upper hand, where different branches of philosophy gradually dominated the bioethical discourse. With the secularization of Western societies, the field also became more secular and religion was eventually pushed to the sidelines. For biomedical scientists, the scholarly weight of their contributions was tied to their ability to employ pertinent secular philosophical approaches rather than their expertise in their own specialization. Besides philosophy, other disciplines keep making contributions to bioethics, including economics, psychology, in addition to social sciences that gained wide currency with the empirical turn in bioethics (Callahan, 1999; Engelhardt, 2000; Jonsen 2006; Veatch, 2006; Shelp (ed.), 2012).

2. Interdisciplinarity in Islamic bioethics. The early history of Islamic bioethics dates back to the beginning of the twentieth century, where individual Muslim religious scholars issued some sporadic fatwas (religious advice) in response to questions related to embryology (Rida, 1910; Ghaly (ed.), 2018). During the 1950s-1970s, the number and frequency of bioethical fatwas considerably increased, with a focus on front-page issues like contraceptives, organ transplantation and assisted reproductive technologies (Jad al-Haqq, 2005).

It was only in the 1980s that Islamic bioethics assumed an interdisciplinary character through the establishment of transnational Islamic institutions. These institutions systematically involved both Muslim religious scholars and biomedical scientists to address bioethical issues (Ghaly 2010; Ghaly 2012). The analysis of this interdisciplinarity, compared to secular bioethics, will be highlighted through the following points:

Religious scholars and biomedical scientists continue to be the main contributors to Islamic bioethics. Contributions made by specialists in other disciplines, including philosophy, psychology and the social sciences, remain minimal or simply non-existent (Awadi, 1985).
The role of biomedical scientists was initially conceptualized to be limited to explaining the technical biomedical aspects to Muslim religious scholars. Despite some religious scholars' reservations, biomedical scientists keep trying to widen the scope of their role by actively participating in the very process of religio-ethical reasoning and the resulting normative judgments (Ghaly 2013; Ghaly 2015).
The role played by religious scholars remains crucial in shaping Islamic bioethics. However, they are criticized for their narrow focus on Islamic jurisprudence, whereas significant disciplines, like Islamic theology, philosophy, and Sufism are hardly represented.
A new generation of bioethicists in the Muslim world, who function as a bridge between Muslim religious scholars and biomedical scientists, is on the rise. However, the transdisciplinary communication between specialists in secular bioethics and their peers in Islamic bioethics is still sporadic, unorganized and in need of support from institutions like ESPMH and IAB (Ghaly (ed.), 2016).

Boundary work in the health care for people with variations of sex characteristics in Europe

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The Chicago consensus statement introduced new guidelines for the treatment of people with variations of sex characteristics (VSC) and support for their families. The statement and its update advocated for new conceptual framework that proposed multidisciplinary teams (MDT), providing health care for people with VSC, accommodation of parental concerns, peer support, patient centered care, open communication, shared decision making and gender assignment. However, there is a lack on data on the implementation of patient oriented multidisciplinary approaches of teams caring for children with VSC and shared decision making between care providers, parents and possibly peer support groups.
To address the lack of data I conducted 7 focus groups with health care professionals and peer support groups in care teams in Central, Northern and Western Europe. The following paper firstly examines opinions of care providers and peer support groups involved in collaboration in health care provided to children with VSC and their families. Secondly, the paper examines viewpoints of team members in the care for people with VSC in the aim to incorporate the growing capabilities of a child with VSC, parental wishes and concerns, open communication, and peer support.
The themes from focus groups about care for children with VSC and their parents are examined by drawing upon the epistemological notion of multidisciplinary and interdisciplinarity that were already suggested in the consensus. It examines how these two notions were implemented in the care for people with VSC as collaboration approaches: how has multidisciplinarity/interdisciplinarity been implemented in the shared decision making and collaboration of the health care teams that provide care for people with VSC and their parents.
The themes from focus groups are examined by drawing upon the concept of boundary work by Thomas Gieryn as care professionals use their knowledge and expertise to inform and support children with VSC and their parents about the variations of sex characteristics, how to accept them and most importantly actively participate in shared decision-making process. Based on the findings from focus groups boundary work as demarcation process between scientific and non-scientific activities is not applied unidirectional. It is not a straightforward

process through which care professionals establish themselves as the sole source of scientific authority by expanding, monopolizing and protecting their professional authority, but I claim it is rather more bi-directional as the collaboration and decision making are becoming oriented to acknowledge peer support knowledge and the growing capabilities of a person with VSC and their personal experience and knowledge. Boundary work is taken to be a complicated process in which demarcation between scientific and non-scientific is blurred by acknowledging the agency of peer support groups, knowledge of people with VSC and their parents for the purpose of making a treatment decision or no decision.

Embodied Aspects of Disease Prevention: Phenomenologically Grounded Approach

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Phenomenology has been used as a qualitative research methodology in health sciences, with or without direct reference to the tradition of phenomenological philosophy. In cases where the phenomenological tradition has been used, two major approaches can be discerned: emphasis on either the phenomenological method (e.g., Giorgi, Smith, and van Manen) or the phenomenological concepts (e.g., Zahavi, Høffding, Martiny, Køster, and Fernandez) as useful tools for qualitative research. In this paper, I will argue for the benefits of the latter approach, illustrating how phenomenological concepts can ground the qualitative research, generating new knowledge in the field of health care. In doing so, I will refer to our study of people's embodied experience of vaccine hesitancy (specifically hesitancy to receive vaccination against COVID-19), in which we have combined phenomenological concepts with qualitative interviews using the framework "Phenomenological Interview" (PI) (Høffding and Martiny, 2016). The aim of this paper is to show that insights about embodied aspects of vaccine hesitancy have implications for understanding the adherence and failure to adhere to the preventative measures in health care.

The theoretical background against which I have developed this study is a conceptual distinction within phenomenology of medicine between illness, disease, and health, where disease refers to the objective pathophysiological findings, illness refers to perceived lived body disruption, and health refers to one's engagement in the world through the lived body (Toombs, 1992; Carel, 2016). Using the conceptual distinction between the lived body and the object body (and the associated distinctions between bodily certainty/doubt and absent/present body), I will argue that based on the results of our research study, vaccine hesitancy can be explained, among other things, with reference to embodied-temporal aspects of one's experience, i.e., vaccination promises to prevent disease, but at the same time, it threatens to disrupt one's lived body, which characterizes the experience of health. Vaccination (either previously received or expected) has an impact on one's embodied being in the world by actually evoking (or anticipating) an objectification of one's own body (through hyper-focus), which leads to the disruption of one's lived body and loss of bodily certainty. Without denying the existence of other factors, this shows that vaccine hesitancy can be grounded in embodied fear of losing trust in one's body and experiencing alienation from it. Thus, while vaccination promises to prevent a disease (e.g., COVID-19), looking from the experiential perspective, it also threatens to disrupt the experience of health, leading to bodily objectification and bodily doubt – aspects that are unwelcome to the experiencing subject as they also characterize the experience of illness.

In conclusion, I will argue that the knowledge gained about the embodied aspects of vaccine hesitancy might be helpful in understanding the broader question of why, in some cases, people are successful in adhering to health-promoting measures, while in others, they are not.

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Coercion and contributory injustice in mental healthcare – an analysis

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Qualitative research demonstrates that service users' understanding of coercion significantly differs from the standard account of coercion in mental healthcare ethics. For example, many instances in which service users recount having experienced coercion are not classified as coercive according to this standard account. This may lead to their testimonies being disregarded by mental healthcare professionals.
In this presentation, I argue that by mental healthcare professionals' and ethicists' reliance on current standard accounts of coercion, service users are exposed to contributory injustice, a specific form of epistemic injustice.
Epistemic injustice describes a person's unjust exclusion from the production and distribution of knowledge. Contributory injustice occurs if people in dominant epistemic positions rely on established concepts and theories while ignoring epistemic resources developed by people in marginalized epistemic positions. Thereby, the latter are unjustly prevented from contributing to a shared understanding of the experiences they make.
Miller Tate defines four necessary conditions to be met for a social group (g) to experience contributory injustice: 1) another group (h) with which (g) regularly interacts shows a significant gap in their epistemic resources, 2) this gap keeps members of (h) from understanding experiences made by (g), 3) members of (g) are significantly disadvantaged through this lack of understanding and 4) the gap in (h)'s epistemic resources is the result of the epistemic marginalization of (g). I will demonstrate that all of these criteria are fulfilled with regard to the account of coercion in mental healthcare.
First, according to the standard account of coercion, an interaction is coercive only if a service user's will is explicitly overridden by legally regulated measures (formal coercion) or if a service user is threatened to be made worse off than they morally ought to be (informal coercion). However, this account does not allow for including interactions as coercive based on relational or contextual factors which are regarded as highly relevant by service users. The epistemic resources used by mental healthcare professionals to determine whether coercion has taken place, thus, show a significant gap.
Second, studies have shown that service users and mental healthcare professionals come to different conclusions when asked to assess the coerciveness of an interaction. Mental healthcare professionals routinely underestimate the amount of pressure they exert on service users. The gap in mental healthcare professionals' epistemic resources – the failure of standard accounts of coercion to consider relational and contextual factors – can explain why they cannot understand service users' experience of coercion.
Third, this leads to service users being unable to meaningfully communicate their experiences – if their testimonies of having experienced coercion do not align with the standard account of coercion, they are likely to be disregarded by professionals. Thereby, service users are significantly disadvantaged.
Fourth, despite service users being most affected by coercion, their perspective fails to receive adequate uptake on the conceptual level. Current standard accounts of coercion were developed

without the involvement of service users and the insights gained from studies involving service users have not yet led to a revision of these accounts. Thus, the epistemic gap is the result of the epistemic marginalization of service users.
After having shown that service users experience contributory injustice with regard to the standard account of coercion in mental healthcare, I will close by arguing that this provides reason to revise this account.

Philosophy of medicine: No method - no discipline
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Methods play a substantial role in the consolidation of disciplines. Disciplines with well-established methods have clearer demarcations and better standings than those who do not. However, philosophy of medicine (PoM) does not have clear methodology. Even more, very few articles in PoM journals include explicit statements about methods. Hence, there seems to be a methodological vacuity in PoM. This presentation investigates several counterarguments against the claim that philosophy of medicine is not a discipline as it does not have a (fairly clear) methodology: 1. The method is implicit and does not need to be made explicit. 2. It is impossible to agree on methodology. 3. Methodological pluralism (as in other fields). 4. PoM does not need method. 5. Philosophy (in general) is the method. 6. You do not need method, but quality criteria. 7. Other aspects are more important than methodology. 8. PoM is a tertium quid (neither discipline, method nor theory as reflected in Gadamer's Wahrheit und Methode). Unfortunately, the scrutiny of these counterarguments does not undermine the hypothesis that PoM would have been a more definite discipline if it had a clear and more explicit methodology.

Organoid models of early human development – When is a model more than a model?
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Research aimed at developing models of stages of early human development derived from stem cells is proceeding apace. There have been many recent publications on blastoid, gastruloid, and embryoid models among others. Such models are important to advance our understanding of early human development. This paper will analyse how we should evaluate these models ethically. The mere fact that, for instance a blastoid is a model of a blastocyst is not in itself dispositive of the ethical importance of that particular type of blastoid. A model is not the real thing, and may be a more or less good model, approximating the real thing more or less closely. In some cases we also have to take account of factors external to the model itself, if for instance the model + some external modification may have functions that the model itself does not have. The analysis will consider a number of different ways to approach the question of the ethical importance or status of these kinds of models:

- Origins
- Ontology
- Function

It will be argued that in many cases no single criterion or factor is sufficient to decide the ethical importance or status of a particular type of model. What is needed is an exercise in abductive reasoning taking into account multiple characteristics of the model, the external context, and the thing that is being modelled. In essence we have to approach the issue along the lines of the

well-known ‘duck test’: “If it looks like a duck, swims like a duck, and quacks like a duck, then it probably is a duck.”

Socio-economic factors of ‘Completed Life’ euthanasia

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Since Dutch parliamentarian Pia Dijkstra submitted a proposal to allow assisted dying for a ‘Completed Life’ (based on existential rather than physical or psychological suffering), the debate surrounding end-of-life ethics has significantly recentred. The eligibility requirements for this new form of assisted dying are that the individual is a Dutch citizen or long-term resident over the age of 75 who no longer wishes to continue living due to a lack of life purpose. This can range from someone who has already achieved every goal they had in mind for their life, to someone who considers their life a series of missed opportunities.

Recently, Els van Wijngaarden has called into question whether the kind of completed life Dijkstra had in mind truly exists. During the government-commissioned study van Wijngaarden led on the demand for this new form of euthanasia, she noticed a theme of financial struggle amongst those who might be interested in completed life euthanasia. This finding is not only fascinating but could be a significantly decisive factor in the course this debate takes.

In this paper I will be building on this initial finding by adopting Sen’s capability approach and applying it to existential suffering. This will require first an in-depth discussion of what existential suffering is and how it can manifest. In this initial section I will explain what is meant by the terms ‘suffering’ and ‘unbearable’. Essentially, neither are necessarily experienced as negative; for the purposes of this paper, I use ‘suffering’ in the Schopenhauerian sense that there is a lack of some sort. In the case of existential suffering, this refers to the lack of a life purpose that makes life worth living. ‘Unbearable’ also does not necessarily refer to the agonisingly painful experience that immediately comes to mind, but rather that the suffering is simply of such an extent that the individual no longer wishes to bear that burden.

I will then use the capability approach to discuss why it is that individuals who are financially struggling might be especially susceptible to existential suffering. Here I will argue that a challenging financial situation can easily prevent an individual from fulfilling their life purposes, and thereby can form an insurmountable obstruction to living authentically. However, this also makes these individuals a vulnerable population which requires an increased level of protection.

Finally, I will examine further what the primary goal of Dijkstra’s proposal is. Supposing it is to alleviate existential suffering, then theoretically the source of that suffering should be less important than the extent of suffering experienced by the individual. In this sense, individuals who are struggling financially should be given the same opportunity as anyone else to make autonomous decisions about the biographical narrative of their own life. However, to make sure this population is sufficiently protected, it is essential this proposal is combined with robust economic policies to alleviate the effects of poverty and offer financial aid to those who need it.

Adaptive preferences and decision-making capacity.

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With both adaptive preferences in feminist philosophy and decision-making capacity in bioethics, the fundamental issue is whether to accept the expressed preference of somebody.
In bioethics, the general idea behind decision-making capacity is that people must be able to make their own decisions regarding medical treatment if they have the ability to do so and have been provided with adequate information. Therefore, people can refuse life-saving treatment such as renal dialysis or blood transfusion. This refusal must be respected, even if the consequence of the refusal is that the patient will die.
In feminist philosophy, it is argued that people's expressed preferences should not always be accepted, as there is the issue of adaptive preferences. Nussbaum described women in Asia who were poorly treated. Somebody had to do physically demanding work for a small wage and still look after her children while her husband was not contributing. Another woman was physically abused in her marriage but had accepted the situation for years.
In Nussbaum's description, there was no evidence of problems with decision-making capacity, even though this is not explicitly stated. Nussbaum also seems to assume that these women had access to information about alternatives. She argued that these expressed preferences should not be accepted because some fundamental rights were violated. Khader argued that one should not accept these expressed preferences because one should encourage flourishing.
The situations seem analogous, making a decision about medical treatment, where one tends to respect autonomy if even the outcome is the death of the person and decisions about one's social situation, such as not leaving an abusive husband, where one does not want to respect the expressed preference.
In practice, the differences are probably not as significant as they prima facie seem. There are many issues people cannot decide freely in western societies, even if they have decision-making capacity. For example, they cannot request abortion and physician-assisted suicide under all circumstances. Furthermore, in acute situations, people can also be treated without consent (e.g., acute blood loss or hypoglycaemia).
Having said that, there are genuine differences. Suppose somebody is stuck in an abusive relationship. In that case, one should not accept the wish to stay in this relationship, but if somebody is under the pressure of a religious community, one should respect the wish not to have a blood transfusion.
Although there is perhaps not one overarching moral theory, there is something to be said for developing one overarching framework for when to accept people's expressed preferences both in bioethics and feminist philosophy.

How proven is a "proven intervention"? Ethics of placebo controls in the light of conditional approval programs for regenerative therapies

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With a focus on regenerative therapies, this presentation discusses the difficulties of establishing whether there exists a proven therapeutic intervention when experimental treatments are made accessible to patients under conditional approval programs (i.e. outside the framework of clinical trials). This discussion is timely in light of a global move towards conditional approvals of therapies, often made on the basis of less robust efficacy evidence than otherwise required for registration of new treatments. The quality of evidence required for a

therapy to become available to patients has been affected by such programs. This influences decision-making on ethical justification of using placebo-control design. The absence of a proven intervention is an important requirement in evaluating whether it is ethically justifiable to use such design in a clinical trial and is present in major ethical guidelines (e.g. the Declaration of Helsinki). The main argument examined in this presentation is that conditionally approved therapies, if referred to as "proven intervention", would make placebo-control design (provided absence of other conditions which would justify disregarding this criterion) ethically unjustifiable. Conducting rigorous clinical trials after conditional approvals is crucial to establish the efficacy of approved therapies. Hindrances to running such trials and generating further efficacy evidence are brought into attention.
The scope of concepts such as "proven intervention" or "established effective intervention" present in ethical guidelines' requirements as to the use of placebo controls risks becoming a matter of interpretation and challenging further generation of evidence about treatment efficacy in placebo-controlled trials. There is a need for an international debate in research ethics and harmonization as to how these requirements should be interpreted and applied in the light of programs which allow patients accelerated access to regenerative therapies on the basis of less robust evidence regarding their safety and efficacy than has been required before these programs emerged.
For instance, de facto clinical use of conditionally approved therapies and the level to which they are supported and trusted by physicians should be considered – they may be formally approved but not trusted and/or used in practice. For some treatments, such as cell or gene therapies, a long-term follow-up may be needed to establish their efficacy, which would fall outside the scope of an often 5-year clinical trial. Knowledge gaps about long-term effects should be borne in mind when analyzing published efficacy results of such therapies.
Public outreach about these issues would help to keep both patients and medical professionals informed about the efficacy status of therapeutic products they are using or prescribing. This would enable their informed decision-making. It is likewise important to reflect on methodological aspects and end points in other methodological approaches where randomized clinical trials cannot be performed due to e.g. limited number of patients. In case other approaches are used, such as single-arm studies, guidance on how to understand the role of non-randomized evidence is needed. Moving towards personalized medicine and precision medicine, where treatment may become available for individual patients actualizes a need to consider novel methodologies.

The Complexity of attending to ethics in practice in the context of data-driven healthcare technology development

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Data-driven healthcare technologies are increasingly being introduced into national healthcare policies. These technologies, primarily based on machine learning algorithms, are surrounded by social imaginaries and hopes of creating faster, cheaper, more precise and personalised healthcare for more people. With the introduction of mobile technologies and the rise of big data, data-driven health has expanded dramatically. Techno-solutionist discourses have now deeply penetrated healthcare and public health, where Big data and machine learning seem to offer ways out of underfunded public health institutions. Especially since the COVID-19 pandemic, implementation has rapidly accelerated. In Germany, health apps can now be prescribed and reimbursed by health insurers. India presented its 'National digital health mission' in 2020, under which every Indian citizen will have a digital health ID. In June 2022

the UK published a policy paper on their digital health strategy, promising a digital future for the health and social care system. The technologies that these hopeful policy narratives are built on are primarily not developed and designed by government institutions or pharmaceutical/medical device manufacturers. Technology start-ups and so-called 'big-tech' companies (such as Apple and Google) are now entering the 'healthcare market' and identified it as a lucrative field for them. Building on the results of an empirical study conducted in the German, Indian and US American healthcare context, in which we interviewed developers of data-driven healthcare technologies, the aim of the presentation is to address the methodological difficulties in grasping these moral visions of stakeholders in this diverse field. Drawing on insights from Science and Technology Studies and our empirical engagement, we want to focus on the methodological possibilities and limitations offered by empirical qualitative explorations of ethics in practice and highlight the gaps between bioethical theories on data-driven healthcare technologies and developers' notion of ethics. From our empirical material, we can retrace that the group of people that are engaged in tech development are a rather heterogeneous group, from medical professionals aiming to change the healthcare sector to software developers who chose to work in data-driven healthcare development because it would offer the most benefits. However, all of them are guided by the idea of technological growth and innovation that is missing in the healthcare sector. We can observe that in the practice of developing these technologies and the negotiations surrounding them, there are several versions of ethics entangled: such as professional/business ethics, tech ethics, traditional bioethical principles and values, as well as ethics as personal or moral ideas of 'goodness'. The coexistence of different ethics in the field opens up new questions for empirical bioethics of how to attend to ethics in practice.

Conditional donation: is it justifiable to have different policies for different kinds of tissue?

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The question of whether donors should be able to set conditions on who can receive their tissue has been discussed by bioethicists,1-3 but so far there has been little consideration of whether the answer to this question should be different depending on the type of tissue under discussion. In this paper, I will compare the donation of organs with the donation of reproductive material such as sperm, eggs, and embryos, exploring possible arguments for allowing donors to set conditions in one case but not the other. After considering three arguments, I find that there is no ethically defensible reason to have different policies between these two cases. Consequently, I conclude that jurisdictions operating with this inconsistency should consider moving their policies into better alignment.

The argument from special procreative liberty

Procreative liberty is the extension of autonomy considerations into the reproductive domain, with Robertson claiming that 'some activities seem so closely associated with, or essential to, reproductive decisions that they should be considered part of [procreative liberty] and judged by the same standards'.4 Here I contend that the translation of autonomy into the realm of assisted reproduction is illegitimate, and the intuitive appeals of this position (which derive from considerations around freedom and liberty) do not carry over into this realm.

The argument from special parental obligations

Here, rather than the mere fact of procreation being what drives a difference, the idea is that there is something special about parenthood that means a person's responsibilities towards their offspring rather than rights over them. However, I argue that the same is true of organ donors

– this action also has consequences, and it is incumbent on potential donors to consider them. An argument therefore needs to be provided for why the relationship between parent and child generates duties – the deontic ones that do not relate to consequences – that would in turn allow for conditions to be set in that domain and not in the organ donation domain.
The argument from gamete donors potentially meeting the people created from their donations Arguments from donors and recipients meeting each other rest on the potential for harm or upset felt by the recipient at knowing that their donor had offensive or exclusionary views. But in the case of organs, it is plausible that a person would be aggrieved by the notion that their organ donor had selected out people of a certain type, according to principles and criteria that the recipient found morally repugnant. This may be the case irrespective of whether someone meets their organ donor.
I therefore find that the three best arguments for a difference in policy all fail. We must therefore strive for consistency of policy in this arena.

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End-of-life decisions in Hungary: The hospital black box

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More than two decades ago, the Hungarian parliament developed new legislation on health care (1997, CLIV. Act on Health Care) which included patients' rights. This legislative framework avoids the use of the term euthanasia. Instead, the law describes the conditions when a doctor can let a patient die with reference to the right of the patient to refuse treatment. "*Allowing the natural course of the disease, it is only possible to refuse life-sustaining or life-saving intervention if the patient suffers from a serious illness which, according to the current state of medicine, leads to death within a short time - even with adequate health care - and is incurable."* The formal procedure for such a refusal is rather burdensome and bureaucratic. There are certainly a great number of end-of-life decisions that are made in hospitals annually. However, there is a lack of reliable information on how end-of-life decision making is practiced. The world of end-of-life decisions are happing in a black box. This talk aims to highlight the importance of opening this black box and describe potential ways that could lead to such opening.

Opening up past futures: Eugenics, family planning and the liberalization of abortion

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During the first part of the twentieth century eugenics had a formative role in thinking about population and human reproduction. However, after the second world war, the status of eugenics being transformed, and its institutionalization significantly weakened if not fully

disappeared. During the cold war period the symbolic tree of the eugenic movement seemed to collapse, but its roots might have survived or even raised into new forms. Probably one of the most overlooked historical trajectories of eugenics was its connection to the liberalization of abortion law. This paper investigates the potential legacies of eugenic thinking with a focus on the trajectories and transformations that can be identified in Europe during the post-war era. The transformation of interwar eugenics into family planning in the 1950's that switched into reproductive rights in the 1980's will be discussed with a focus on selective abortion.

What Does it Mean to Withdraw Consent in Biobank Research?

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In the European Union (EU) and European Economic Area (EEA), tissue donors give broad consent to the use of their tissue samples for scientific research purposes. Whilst the General Data Protection Regulation (GDPR) allows for obtaining broad consent for certain areas of scientific research, broad consent cannot function as a legal ground for processing biobank data. When biobank data processing is not legitimised on consent by the research participant, some other legal ground, such as public interest or legitimate interest, shall be employed to legitimise data processing. This has the important consequence that when a tissue donor withdraws consent, the donated tissue sample will no longer be used for further research, but the processing of accumulated biobank data, including the data derived from tissue samples, may continue. The reason for this is two-fold: the processing of biobank data lies outside the scope of biobank consent, and the right to withdraw consent is the corollary of free, informed, specific and unambiguous consent to personal data processing, which broad consent is not. Failure to inform tissue donors about the fact that consent withdrawal only applies to the use of the donated tissue sample but not to the accumulated biobank data jeopardizes the voluntary nature of biobank consent. Thus, potential tissue donors should be informed about the scope of consent withdrawal. That is to say, potential tissue donors should be informed about which actions become legally impermissible after consent withdrawal and which actions may continue despite the consent withdrawal.

Can we distinguish good reasons from bad reasons in a systematic review of reasons? A basic quality appraisal regarding reasons for acceptable risk in Human Challenge Studies

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Background: Systematic reviews of reasons map the reasons given in the literature for or against various solutions to a certain problem. However, such reviews currently tend to forgo quality appraisal beyond more pragmatic criteria (such as only including publications published in peer reviewed journals) when in- and excluding literature. This is partly because a systematic, unbiased and feasible assessment of reasons seems to be difficult for theoretical and methodological reasons. In the present project, we attempt to innovate the methodology of systematic reviews of reasons by subjecting the reasons to basic argumentative standards, introducing quality appraisal at the step of literature analysis. We demonstrate this approach by using the example of a systematic review of reasons on the ethical requirements for human challenge studies (HCS). Such studies are experimental clinical trials in which subjects are intentionally infected with a pathogen in order to better understand the course of the disease or to test the clinical effectiveness of a drug or vaccine. HCS promise faster results and more

efficient use of resources, but raise ethical concerns above and beyond the issues encountered in usual trials.
Method: We conducted a systematic review of ethical requirements for HCS and of the reasons given for these requirements. For this purpose, we identified 194 publications from 2001 to 2022 by searching four databases and applying specific inclusion and exclusion criteria. We extracted all ethical requirements and their justifications and sorted these into thematic categories. Focusing on the question of permissible risk for research subjects, we examined which requirements are undisputed and where major controversies exist. We applied two basic argumentative standards to the reasons of these requirements: a reason must be logically independent from the requirement for which it is a reason, and it must be a consideration in favour of this requirement.
Results: The question of acceptable risk for participants is a key controversy in the literature on HCS. Whereas the general requirements on risk are uncontroversial, these have been specified in very different ways. Various reasons are given for these positions. However, a considerable number of these do not meet the basic argumentative standards that we presuppose, even if these are interpreted liberally. This holds in particular for the reasons in favour of risk-averse positions.
Discussion: Our example shows that basic argumentative standards for reasons can be integrated into the methodological framework of a systematic review of reasons. These standards function as a basic quality appraisal. However, applying them does not settle the question which risks are permissible. It merely reduces the field of reasons given for different positions. In a next step, the remaining reasons would have to be considered in depth. It can be hoped that applying clear argumentative standards will lead to a higher argumentative level of the debate.

Rehabilitating Gadamerian hermeneutics: a feminist epistemological perspective on the algorithm-physician-patient triad

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As algorithmic decision-making models (ADM) are increasingly entering clinical practice, they introduce novel challenges for patients and physicians alike. While the literature on AI ethics in medicine has been primarily concerned with topics such as explainability, transparency, and algorithmic bias, social epistemologists have recently emphasized the impact of ADMs on the patient-physician relationship.
While it is unlikely that ADMs will replace physicians altogether, it is within reasonable expectations that these models will increasingly serve as aids in diagnostic or therapeutic deliberations potentially changing the nature of clinical decision-making (Hatherley 2020). Given the epistemic prowess of ADMs – both in terms of access to evidence and efficiency – it is argued that physicians might be held to an epistemic obligation to follow algorithmic recommendations (Bjerring and Busch 2021; Grote and Berens 2020). Other authors have been quick to suggest that a physician's epistemic authority is not exhaustively attributable to their possession of adequate biomedical knowledge – doctors are not mere purveyors of biomedical information – calling for more nuanced appreciations of the epistemic practice of clinical care (Popowicz 2021; Funer 2022).
One prevalent source of inspiration for this body of literature is German philosopher Hans-Georg Gadamer's application of hermeneutic phenomenology in medicine (Gadamer 1996). Building on his original account of philosophical hermeneutics developed in Truth and Method (Gadamer [1960] 2014), Gadamer conceives the ideal clinical relationship as grounded in

dialogue and (empathic) understanding (Svenaeus 2003; Gadamer 1996). Popowicz (2021) and Funer (2022), for example, point out the non-evidentiary epistemic roles of physicians to argue for an interpretative and dialogical understanding of clinical interactions.

While these recent recuperations of Gadamerian medical hermeneutics undeniably highlight essential aspects of this debate, I address two under-theorized elements. First, in many of these discussions, the patient is conspicuously absent; their epistemic contributions rendered only of secondary importance. Second, in relying on idealizations of the physician-patient relationship, many of these authors tend to disregard empirical evidence of the normative force these algorithms have in deliberative and decision-making procedures (Crompton 2020).

In this paper, I draw upon feminist engagements with Gadamerian hermeneutics (Code 2003) to explore their potential for explaining in the dynamics of the ADM-physician-patient relationship. By drawing connections and exposing dissonances between feminist epistemology and philosophical hermeneutics, I bring these two neglected aspects in recent engagements with medical hermeneutics to the fore.

Through a feminist rehabilitation of two critical elements in Gadamer's hermeneutics: 'the Other' (Fiumara 2003; Fleming 2003) and the relation between 'tradition' and 'authority' (Johnson 2003; Homan 2021), I aim to reclaim (epistemic) space for the patient in the patient-physician-ADM triad. Simultaneously, by taking concerns about algorithmic authority (Crompton 2020) seriously, I want to draw attention to (structural) epistemically unjust elements of the clinical encounters reinforced through uncritical implementations of ADMs (Carel and Kidd 2014). As such, I contend that rehabilitating Gadamerian hermeneutics through a feminist lens is helpful to substantiate the patient-centered goals embodied in Gadamer's original conception of the clinical encounter.

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The beginning and the consequences of choosing medical instead of only legal ethical values over a period of 40 years

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In my contribution I intend to (1) describe the *developments* of the Dutch practice of 'euthanasia' in quick steps, those of the stages of confrontation, acceptance and integration, by focusing on:

- the *players in the field* (public/the voluntary euthanasia society, medical profession, the legal institutions and politics/parliament),
- *court ca*ses plus (unexpected) conclusions
- the relatively *'lean' structure* of the 'Euthanasia Law' from 2002, and

(2) focus on developments from that period on, covering:

- the growth in *absolute numbers*,
- the expansion in *additional medical indications* for euthanasia based on the condition of 'unbearable suffering' (psychiatry/dementia/compilation of diseases of the elderly),
- the role of a *new player* in the field since 2012: the Life Ending Clinic/Expert Center Euthanasia: doctors without prior treatment relationship, and

(3) focus on *still existing frictions and expectations* concerning the issues of 'euthanasia and dementia' and societal debates on in-/excluding 'euthanasia and having a completed life' without a medical indication.

How informative were early SARS-CoV-2 treatment and prevention trials? A longitudinal cohort analysis of trials registered on ClinicalTrials.gov

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The concept of clinical trial informativeness was described by Zarin and colleagues (2019).[1] An informative clinical trial is one that makes a meaningful contribution to science, clinical medicine, and patient care. For a clinical trial to be considered informative, it should: 1) ask an important question, 2) be designed to provide a clear answer, 3) be feasible, 4) be scientifically valid, and 5) report results in a complete and timely manner. The purpose of this presentation is to summarize the results of a longitudinal cohort analysis that assessed the prevalence of informative COVID-19 clinical trials.[2] I will outline how data reported in ClinicalTrials.gov, the international clinical trials registry, can be used to assess the informativeness of clinical trials.

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Deconstructing the Concept of Participation in Participatory Health Research: Its Limitations and Opportunities

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Over the past two decades, there has been a global trend towards participatory health research (PHR) and it is becoming increasingly important in health research (Wright, 2021). By involving social actors in the design, implementation, and dissemination of research, PHR aims to improve health research and make research more relevant for those who are the object of it (ibid.). Moreover, influenced by the action research tradition, PHR also aims to initiate change in the life-worlds of social actors and to contribute to health equity in society by prioritizes the needs and experiences of social actors and empowering marginalized stakeholders by giving them a voice (ICPHR, 2021; Brown, 2022).

The current dominant ideal of participation within PHR, however, does not adequately reflect the challenges of participation in practice, as this ideal fails to capture the relevance of overarching socio-structural health research structures, or so we argue. We therefore propose a novel non-hierarchical conception of participation in health research, based on considerations by Wahl et al. (2022), that includes the level of the socio-structural conditions under which health research takes place.

More specifically, we deconstruct the ideal of participatory health research and reconceptualize it considering the novel non-hierarchical model with reference to the socio-structural level. First, originating in action research with a strong political component (e.g., Arnstein, 1969), current models of PHR are hierarchically structured in which academic researchers have the role to empower the stakeholder-group (e.g., Arnold et al., 2022). In doing so, however, these models convey implicit hierarchies that favor both power and knowledge imbalances and are thus in contrast with the ideal of an equal relationship between co-researchers and academic researchers. We argue in response that health research structure must allow and even stimulate learning processes among all stakeholders, academic and co-researchers alike. Furthermore, participatory research depends on all stakeholders having certain capacities that enable

collaborative work, the recognition of different types of expertise and the transfer of knowledge within the research group: for example, academic researchers need to have (basic) health literacy of the disease they are researching, and co-researchers need to have (basic) literacy in empirical research. Yet, acquisition of such capacities requires the structural support from research agencies. Lastly, the quality of the participation, and the collaboration between stakeholders, depends not only on an equal status and the acquisition of literacies, but also on the structural circumstances in which the cooperation takes place. For example, structural deficits, such as a lack of remuneration for stakeholders and short-term funding duration. Being aware of the influence of these aspects on the collaboration enables academic as well as co-researchers to situate their own goals and interests in participatory processes and to reflect on their own role in the process.
With our novel non-hierarchical model of PHR, we aim to provide an understanding of PHR´s participatory ideal that includes its socio-structural limits. This new understanding of participation therewith should ensure the on-going quality of participatory processes and counteract actions that make participation into a mere "tokenism".

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Transformative medical ethics: A framework for changing practice according to normative ethical requirements and its application to medical decision making

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In this presentation we propose a step-by-step methodological framework for translational bioethics which we call transformative medical ethics. It proposes strategic activities that support the realization of ethically justified requirements in biomedicine. This innovative framework is a basis for theoretical and methodological considerations in an interdisciplinary research program where philosophers, social scientists, physicians and other stakeholders collaborate towards a joint aim.
Transformative medical ethics is applied to change a practice according to normative-ethical requirements and analyze this change throughout the process through research activities. It becomes especially important when there is a gap between widely acknowledged, ethically justified normative claims and their realization in the practice of biomedicine.

Building on prior work on translational bioethics, the framework for transformative medical ethics maps a process with six different phases. The six phases involve 1) the concretization of normative requirements, 2) the identification of conceptual action models, 3) the transfer of conceptual action models to practice models, 4) the contextualization of practice models, 5) the multiplication of practice models and 6) the endorsement of practice change. Depending on the phase, research activities might involve conceptual or philosophical research (earlier phases) or empirical social science research (later phases). The framework will be illustrated with the example of realizing respect for autonomy through practice models for medical decision-making.
The framework can be used as a heuristic tool to situate one's own project in the context of a broader translation and transformation effort. This can be helpful to identify the requirements, but also the starting points for subsequent research as well as to promote the interdisciplinary cooperation required for this purpose. It may also help to identify barriers to the transformation process. Furthermore, it can provide guidance for researchers and practitioners to develop appropriate models for action in accordance with ethical norms, which are then implemented and evaluated in specific practice contexts. Further research is required, e.g. to underpin the framework theoretically and to clarify in which cases it should (not) be applied. The framework should also be applied to other examples of bioethics inquiry and has to be evaluated regarding its feasibility and effectiveness in various practice areas. Nonetheless, the framework of transformative medical ethics suggests a systematic and strategic process to investigate and promote practice change that is ethically informed in all phases.

A proposal for a constructivist procedure-based ethical framework for One Health approaches

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There has been an expansion of public health as a response to threats from diseases that strikes both humans and animals, effects on humans due to loss of biodiversity as well as changing life surroundings due to climate change. Several transdisciplinary approaches have arisen since the beginning of the 2000s with a multispecies focus on health. Examples of these are One Health, EcoHealth and Planetary Health and they are favored and proposed by global organizations such as the WHO, FAO, WOAH and World Bank. These broad approaches might need one of the widest versions of bioethics due to their focus on health aspects of humans, animals, plants, and ecosystems, as well as their multicultural and transdisciplinary focus. This implies that an ethical framework needs to bridge the divide between anthropocentrism, zoocentrism, and biocentrism, as well as acknowledge pluralistic ethics. The value-base within the approaches is today both western scientific and traditional knowledge (Indigenous Peoples). At present day, bioethics has only touched this area of research, policy formation and implementation of health interventions.
In this talk I will present a tentative procedure-based ethical framework that might be suitable for One Health approaches. It has been developed from my ongoing analysis of the underlying values of these approaches as well as an extensive study of possible alternatives that could be used in this still rather pristine field of bioethics. The ethics needed is a constructivist deliberation framework where there should be a procedure for choosing those participating in the deliberation, the core values included, and what ethical approach that is most suitable in reaching a deliberated and fair decision. This open version of ethics seems at the moment most suitable to these bioethically complex approaches and could also meet claims from pluralistic ethics without ending in an “anything goes”-ethical mishmash.

Phenomenological Bioethics and the Narrow Scope of the "Conscious Neural Organoids" Debate

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In the bioethics and neuroethics literature, there has been much speculation concerning the possibility of neural or cerebral organoids attaining consciousness. This has led to a debate regarding the ethical permissibility of conducting research that may, intentionally or not, yield organoids with the capacity for consciousness. In this presentation, I not only appeal to the current state of organoid research to downplay these concerns, but also argue that if there were scientific justification for taking these concerns seriously, then the scope of the current debate is unjustifiably restrictive given its assumptions concerning the conditions and capacities for phenomenal consciousness. Articulating central principles in phenomenology and appealing to evidence in embodied cognitive science, I demonstrate that we have good reasons to be sceptical about in vitro neural organoids and assembloids possessing a capacity for consciousness that would yield phenomenal conscious experiences similar to the phenomenal content of human consciousness. As a result, there are good reasons to broaden the scope of the debate about whether research involving neural organoids warrants special ethical or legal concern.

Doing Body, Making Home, and Becoming Oneself: A Case Study for a Critical Phenomenology of Dis/ability

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This article aims to contribute to the understanding of the embodied experiences of persons living with disabilities against their lifeworlds from a critical phenomenological perspective. While many studies tend to focus on disability experiences as socially constructed, objectified, and marginalised, I propose an alternative and nuanced account that emphasises the "I can" schema as the underlying structure of embodiment. Using the first-person lived experiences of a mother and daughter with Osteogenesis Imperfecta(OI) in Taiwan as a case study, this article attempts to flesh out the ways in which people live through their disabilities interwoven with socio-cultural and political contexts through three themes that emerged from my phenomenological analysis: doing body, making home, and becoming oneself. Taking a critical phenomenology stance, I do not merely articulate their self-experiences but take critical distance from them to study their constitutive conditions ("a historically-grounded, quasi-transcendental critique", Guenther, 2021) and consider the multidimensional interplay of social norms and power relations in the way people experience disability across their life course. By drawing attention to the social processes at work in the normative construction of the "I can" schema, within which the mother and daughter with OI lived, I argue that the "I can" structure behind their lived experiences of the body, illness, home, belonging and self-identity is framed by the complex intersection of ableism and sexism. In light of this contention, I then turn to examine Kristian Martiny's proposal of phenomenology of disability in relation to Iris Young's feminist phenomenological account of inhibited intentionality.

Patients' option not to know on a trajectory towards the end of life

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Should patients be able to refuse information about their diagnosis, prognosis, or treatment options that a doctor wants to convey? The presumed right not to know is set out in influential codes of ethics and legislation, but whether patients should have such a right is disputed. The debate has focused on patient autonomy and what might be in the patient's best interest, as well as a potential duty towards others who might be negatively affected by the lack of information. Less debated is whether there are things that patients are morally obliged to learn about themselves in order not to abdicate their status as moral subjects. In this presentation, I will explore this question in the context of patients with chronic kidney disease who receive maintenance dialysis treatment. Early advance care planning with these patients and their relatives is usually considered important by nephrologists, but there are patients who prefer not to be informed about their expected future situation and who do not want to make any decisions in advance, even when death is imminent. I will argue that, in these cases, there might be things that the patient ought to know, not only for acting autonomously or because this knowledge serves the patient's best interest, or even as a duty towards others, but as an obligation towards herself as a moral subject.

Experimental philosophy of medicine: using a qualitative study to explore conceptual issues in medicine and healthcare

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In the medical-philosophical debate, 'health' and 'disease' are primarily approached as theoretical concepts without exploring their actual use in practice all too much. The relevance of defining health and disease concepts is therefore not always clear. While recognizing possible practical consequences of defining health and disease in certain ways, philosophers tend to depart from theory instead of practice. Although theoretical cases may help to explore and elucidate how health and disease could be defined, they usually do not provide information on how these concepts are embedded in the various practices they are deployed in. Problems with proposed definitions (e.g., medicalization and overdiagnosis) are commonly discussed as general problems concerning the definition itself instead of being context specific. Consequently, it is often not clear till what extent such problems are in fact experienced as problematic in practice and for whom exactly it is a problem. Hence, we suggest that the theoretical debate could benefit from incorporating empirical research.
In this talk, we will discuss the results of the qualitative interview study we conducted. The study explored how health and disease concepts are used in practice and what kind of problematic situations are experienced in practice in relation to definitions or approaches that are being used. We have conducted qualitative interviews with a broad range of professionals and patient representatives (N=17), working in various health-related disciplines, fields and organizations. From the interviews, we highlight several different practical functions of definitions of health and disease, that are considered to have different roles and effects depending on the context they are used in. Furthermore, we discuss 5 types of problematic situations that emerged from in the interviews. Underlying to these problematic situations we observe several different conceptual issues. This qualitative study gives insight into the views and experiences of a group of various medical professionals and patient representatives regarding the conceptualization of health and disease concepts in practice and possible

problems that surround them. By connecting their views and experiences to the theoretical debate, we hope to contribute to a more pragmatic way of understanding the relevance and significance of conceptualizing health and disease.

Ways to an integrative and transdisciplinary approach in empirical ethics – Methodological considerations from interdisciplinary ethics research on digitization in healthcare

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In my contribution, I anticipate the various aspects, challenges, and solution strategies of empirical ethics research based on several different completed and currently ongoing projects from a social science perspective. These are carried out at the Institute for Medical Management and Health Sciences at the University of Bayreuth from 2017-2023. All projects are at least interdisciplinary cooperation projects involving researchers with different normative perspectives from bioethics and medical ethics as well as researchers from Bayreuth with health sciences, cultural-, social sciences, and sociological backgrounds. International (PROFID-Project), national projects (e.g. Medicine 4.0) as well as projects with specific institutional prerequisites (e.g. DiNa4U-Project) are included.
The aim of the contribution is to present some essential aspects of the independent development of a methodologically reflected and pragmatistic variant of interdisciplinary empirical ethics research based on these experiences, which understands itself as a transdisciplinary-oriented empirical-informed and iteratively inclusive, context-sensitive research on ethical issues. Both the respective methodological approach and the integration of developing (intermediate) empirical results into the philosophical analyses of different starting points will be discussed.
A particular focus of the contribution is on qualitative social science and sociological research. Thereby, a perspective of the concepts "art of research" and "research as work" by Anselm Strauss, which has many references to his grounded theory methodology, will be introduced. In addition to this, practical research experiences of the projects, all of which include comprehensive multilayered mixed methods designs, are incorporated. It will be shown how a specifically adapted mutual integration can function in feasible a manner by using various examples of methodological and epistemological challenges in different phases of the research process. Everyday challenges as well as gaps of proto-scientific self-conceptions and identifications of researchers in and outside their disciplines are also outlined in this regard. This concerns praxeological and research economic prerequisites as well as 'language' and 'habitus' barriers of respective disciplines and perspectives.
The content orientation of all presented projects is grouped around ethical issues in the field of digitalization in healthcare. This includes questions about mhealth, telemedicine and integration of internet-based technology in healthcare as well as Big Data approaches and Artificial Intelligence.
In a nutshell, transdisciplinary research is an increasingly popular approach to tackling complex societal problems, also in empirical ethics. However, conducting such research poses methodological challenges, particularly in terms of integrating empirical and ethical analyses. This contribution explores the benefits of combining social science research with philosophical and ethical analyses to promote a successful iterative integration of descriptive and normative perspectives, methods, and analyses and therefore shows different examples and ways to make those goals successful.

Research ethics guidelines for global crises: "distilled existing" or new?

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It has been more than four decades since core principles, relevant to research involving human subjects, were identified by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research in the *Belmont Report*. Three fundamental principles (respect for persons, beneficence and justice) were supposed to assist scientists, subjects, reviewers and interested citizens to understand the ethical issues inherent in research involving human subjects. Other research ethics guidelines, such as the *WMA Declaration of Helsinki* or *CIOMS Guidelines for Health-related Research Involving Humans*, introduced a more detailed and specific list of ethical principles aiming to provide an analytical framework that could guide the resolution of ethical problems arising in the context of research involving human subjects. However, the first quarter of the 21st century has been marked by a number of disasters, such as tsunami, pandemics and military conflicts, which raised specific challenges for conducting research. The need to adapt a general research ethics framework or to develop a new framework applicable for different types of disasters triggered a number of initiatives to develop more specific ethical guidelines. For example, regarding just COVID-19 research, a number of international and national organizations (such as WHO, PAHO, EMA, FDA, the Nuffield Council; MHRA; Austrian Federal Office for Safety in Health Care; University of the Philippines Manila; Uganda National Council for Science and Technology just to mention a few) developed guidelines aiming to assist researchers, research ethics committees and other stakeholders involved in planning, reviewing, conducting research and disseminating research results during pandemics.

Preliminary desk analysis of principles used in the research ethics guidelines for global crises (especially for COVID-19) revealed that crises-driven research challenges sometimes do not map clearly onto existing ethical frameworks and therefore new/additional important principles are introduced (or existing principles prioritized in a different way). One such example is the principle of "solidarity", which has become a driving force in the ethical discussions around COVID-19 pandemics (Chatfield K., Schroeder D. 2020). Another novel feature of recent research ethics codes, applicable in pandemic as well as non-pandemic contexts, is that some of them (e.g., *TRUST Global Code of Conduct for Research in Resource-Poor Settings)* integrate research ethics and research integrity principles, which traditionally had quite clear separation in research ethics and research integrity debates.

Therefore, this paper aims at reviewing codes and guidance applicable to research during global crisis with a specific focus on Covid-19 pandemic. In particular, it analyses what new principles, if any, are included in research codes or guidance, how these principles are defined, do the meanings of the defined principles align with each other.

Ethical perspectives on the traditional cost-effectiveness evaluation for the application of immunotherapy in the treatment of NSCLC

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Lung cancer is the number one cancer-related mortality cause worldwide and less than 20% of patients survive five years. More recent therapeutic modalities, like combination immunotherapy, are offering hope for new treatments. However, despite clinical evidence of drug superiority, these drugs are mostly considered not cost-effective due to their high costs per life year(s) gained. This presentation, taking an ethical stand, reevaluates the preconditions of

the current and potential immunotherapeutic treatments for NSCLC with a focus on cost-effectiveness analysis of exemplary treatments. To do so, we will discuss the concepts of medical applicability, social desirability, and ethical justifiability of immunotherapy for the treatment of NSCLC. We will then attempt to provide an answer to whether the current methods for cost-effectiveness or risk-benefit analysis are the appropriate choice for the evaluation of immunotherapeutic treatments or there is an ethical argument for a particular focus on the need of the patient population using Amartya Sen and Martha Nussbaum's theories of capabilities and functions.

(Too) soon, (too) late? An empirical investigation of moral intuitions regarding the appropriate timing for becoming parents.

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The widespread availability of contraceptives and birth control measures in many countries has arguably had an impact on the timing when people have their first (and last) child. Other changes at a societal level, such as the availability of education for longer years and the decline of the 'breadwinner' model in family formation, have also contributed to this shift. Moreover, the availability of Assisted Reproductive Technologies (ART) increasingly facilitates having children at moments in life where this was not possible in the past, by – for example – allowing postmenopausal women to bear a child conceived through egg donation. For this reason, the topic of timing of childbearing has been sparking a heated debate in society and in the research community, which is centred on the discussion of when it is (too) early and (too) late to have children. The latter issue has been particularly discussed in the bioethical literature, where views are divided on whether parents of an Advanced Parental Age (APA) are wrongfully impacting the well-being of their children or whether having children after a certain age represents a legitimate exercise of reproductive autonomy.
In this presentation, we follow the methodological approach of normative empirical reflexive equilibrium to analyse people's moral intuitions on the appropriate timing for childbearing. More specifically, we draw from data collected as part of a large project on family building at an advanced parental age where we interviewed more than 50 people on different aspects related to childbearing later in life. Our interviews were conducted in Switzerland with children of parents of an APA (defined as 40+ at the time of birth), APA parents who had a child through ART, medical professionals who have been assisting APA parents to conceive a child through ART, and aspiring APA parents who were trying to conceive a child through ART at the time of the interview. Our interview-guide contained some parts based on elicitation techniques, where we stimulated participants to reflect on the appropriate timing for childbearing. We analysed their answers and reflections related to these issues by coding the moral intuitions that participants expressed in regards to when is (too) early, (too) late, or ideal timing for becoming parents. We then used these moral intuitions and fed them into the process of reflective equilibrium, to then draw normative conclusions concerning the (appropriate) timing for childbearing. In so doing, we also outline some considerations on the use of this methodology in the growing field of empirical bioethics.
[408 words]

The interaction between law and bioethics in addressing international organ trafficking

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Substantial recent developments in law and ethics to combat international organ trafficking raise the question how the two should interact. How much should be done by law, and how much by bioethics? Is there a sensible division of effort between the two? Is there a potential conflict between the two? Do the developments in one require developments in the other? These are the questions that paper would address.

The Council of Europe Convention against Trafficking in Human Organs now has fifteen ratifying states and eleven other states which have signed the Convention but not yet ratified it. That Convention obligates states parties to prohibit its nationals and habitual residents from engaging in organ trafficking whether inside or outside the territory of the state party. There are five states not party to the Convention which have also enacted the legislation the Convention requires.

The International Society for Heart and Lung Transplantation made a statement on transplant ethics in April 2022 that "the body of evidence that the government of the People's Republic of China stands alone in continuing to systematically support the procurement of organs or tissue from executed prisoners" is sufficient to justify a prohibition on papers and publications "related to transplantation and involving either organs or tissue from human donors" in China. The NGO Global Rights Compliance in April 2022 released a Legal Advisory Report and a Policy Guidance, both under the title "Do No Harm". The subtitle and subject matter of the report is "Mitigating Human Rights Risks When Interacting with International Medical Institutions & Professionals in Transplantation Medicine".

The paper would look at these developments in law and ethics in the field of transplantation and their implications for the further development of the law and ethics related to transplantation. Law and ethics in this area are being developed piecemeal. The question becomes what a comprehensive approach would look like.

The analysis would proceed by way of a case study, considering transplant tourism to China that benefits from organ harvesting of prisoner of consciences, primarily practitioners of the spiritually based set of exercises Falun Gong, also Uyghurs in large numbers, and Tibetans and House Christian, notably Easter Lightning, in lesser numbers. The paper would address practically the implications of the present and proposed legislation and the development of ethical standards on counselling patients who could potentially travel to China for organ transplants and on collaboration between foreign transplant professionals and their Chinese counterparts.

The ethics of the transplant profession right now are not specific enough to address the latest legal developments. Detailed suggestions about what those specifics might be would be offered. Legal developments, independent research and ethical advances made by some components of the transplant profession manifest a need by the transplant profession generally to articulate more specifically the ethics of the profession relating to cross border organ transplant abuse. The paper would make suggestions of what those specifics could be.

Citizen-centred approach to public engagement on the ELSI of health technologies

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Citizen engagement on ethical, legal, and societal issues (ELSI) of health technologies is a relatively recent but growing field with a wide variety of methods and no shared standards.

Citizens are engaged for different purposes (e.g. education, sensitization, feedback on research projects, co-creation in governance) through various tools (e.g. surveys, qualitative interviews, deliberative forums) on varying scales (local, national, international) and in diverse contexts (e.g. policy-making, research, or field-based issues). Given the increased calls for citizen engagement, it becomes urgent to reflect on its practices holistically and critically and share challenges, lessons learned, and suggestions for best practices from that perspective. Based on our cumulative experience with regional, national, and international citizen engagement on the ELSI of health technologies, we take that step back to ask ourselves two critical questions:

1. What is the essence of citizen engagement, regardless of the methods used? In other words, what should all citizen engagement initiatives have in common to be considered meaningful?
2. What are common challenges and best practices to ensure meaningful citizen engagement?

In the past, citizens were usually approached strategically using one-way communication from the experts to the "ignorant" people to enhance their literacy and trust in science and promote its benefits to gain support. If this 'deficit model' is now criticized and old fashioned, it sometimes persists in the mind-set of policymakers, scholars and practitioners, who thereby perpetuate power imbalances from society into the engagement process, between those who engage and those who are engaged. Hence, the engagement practice is shaped by the expectations and needs of powerful actors.
In response to this, we argue that the more citizens are put at the centre of the process, the more the engagement practice becomes meaningful, regardless of the methods used. We define the citizen-centred approach as the empowerment of citizens by focusing on their perspectives (e.g. values, concerns, needs, and experience) and considering them as equal partners, as far as is feasible, in the engagement process. This way, citizens are enabled to add their unique contributions as lay stakeholders and have a say on issues impacting them.
With that essence of citizen engagement in mind, we developed a set of suggestions for best practices to conduct citizen-centred engagement based on our lessons learned and the challenges we encountered. These are:

1. Be as transparent and honest as possible towards citizens regarding the process and use of the outcomes;
2. Minimize hierarchy to create a 'safe island of democracy';
3. Trust the process and what citizens can add;
4. Interpret, present, and disseminate the outcomes as objectively as possible;
5. Make engagement a continuous process, not a single event.

Through this reflection, we invite any stakeholders who can positively (empower) or negatively (disempower) impact the role of citizens in the engagement process to think ethically about their power and, consequently, their responsibilities towards citizens.

Getting one level up: Insights about the methods, the reporting and the use of (systematic) reviews of ethics literature. An example of meta-research of secondary research in bioethics

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The use of secondary research in bioethics in the form of (systematic) literature reviews has increased significantly over the past two decades (1). In addition to reviews that search and summarize the results of empirical studies (1,2) – and whose results are (also) relevant from an ethical point of view –, another type of review has emerged: reviews in which normative content (e.g., ethical issues, concepts or reasons) is searched for, analyzed, and synthesized into comprehensive overviews (1,3).

However, such systematic reviews of ethical literature (SREL) use adapted and often more qualitative methods than the established systematic reviews known from medicine (1,3). For example, quality appraisal differs considerably and must currently be regarded as having only limited feasibility (4). The assessment of what constitutes good reporting in such reviews are also not exactly the same, as established reporting standards have to be modified to address the specifities of SREL (1,3). Finally, it is not clear how exactly SREL are actually used, whether this use differs significantly from systematic reviews in e.g. medicine, and what the impact of that would be (5).

The fact that information about these methodological differences, challenges and open questions can be provided at all is the result of meta-research – and specifically meta-research that does not examine the methods in medical research, but rather examines the methods of bioethics itself, including their characteristics, implementation and quality, and consequences for bioethics research. To be precise, it is an example of the application of meta-research of bioethics to secondary research methods in bioethics.

The presentation will therefore summarize the results from this already conducted meta-research on SREL (1-5) and thus address the question of whether and to what extent the application of these methods of secondary research, i.e. SREL, is useful for bioethics. On the other hand, the value of this particular form of meta-research for bioethics, i.e. researching research methods that are (newly) used in bioethics, will be discussed.

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Piecemeal social engineering vs. holistic social change? How an interdisciplinary animal research ethics of biomedical research may reconcile diverse perspectives

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Animal experimentation has been a controversial issue for decades. This is especially true for biomedical research, where results of animal experiments are intended to benefit humans in the form of new therapeutic possibilities but inflict harm to the animals.
Many animal ethicists doubt that animal experiments can be ethically justified at all and see their abolition as morally required, implying a more or less holistic social change. Biomedical research ethicists and researchers conducting animal experiments are rather concerned with reducing the harm that animals suffer without compromising the quality of the research results. They therefore tend to focus on piecemeal engineering, i.e., turning various small-scale "adjusting screws" in order to ethically improve the short- and medium-term situation.
Various scholars have been trying to bring these perspectives more closely together. The idea is to shift the debate from a rather abstract pro/con debate towards more concrete solutions. However, ethical questions occur at different points in the course of an animal experiment: from the (legal) basis of (dis)allowing experiments in the first place (project goals, animals used, severity of harm, etc.), to the approval, planning and conducting of an experiment, to the publication of results and possible project evaluation. A further complication is that these issues are characterized by a dependence on cultural imprints and different national legal requirements. This is why an "animal research ethics" is only conceivable as an interdisciplinary endeavor that includes normative as well as empirical disciplines.
Such an attempt to identify different perspectives in an interdisciplinary context, to work out current essential ethical challenges and also to explore possible solutions took place within the framework of an international retreat week. Based on presentations and discussions between junior and senior researchers from various disciplines (e.g. philosophy, law, laboratory animal science, veterinary medicine), the challenges identified included, inter alia, the lack of shared best practice standards, the difficulties that ethics committees face when evaluating a project proposal, and the theoretical and practical complexities of the harm-benefit analysis (HBA). Also, limitations of the established 3Rs (Replace, Reduce, Refine) as an ethical guidance were highlighted. It also became clear that results must be published more transparently, even if they are negative. Furthermore, improvements in the structure and processes of ethics committees, a revision of the ethical review process and of HBA, as well as more training in animal-free methods are needed. Ultimately, national and supranational animal protection laws must be adapted accordingly.
It also became evident in the discussion that the desire for longer-term social change – if advocated – with respect to animal experiments need not oppose short- and medium-term piecemeal engineering. To achieve progress, however, it remains important that animal and research ethics, law and the sciences jointly shape the practices of (future) animal research, and that researchers engage in more and better communication between the scientific disciplines and scientific communities involved. An interdisciplinary animal research ethics that does not draw its normative considerations unilaterally from animal ethics or research ethics can provide a suitable theoretical and social framework for this.

Responsibility, carriership and preconception expanded carrier screening

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A preconception expanded carrier screening (PECS) test is a test a couple can take before trying to get pregnant to see whether both of them are carriers of the same autosomal recessive disease and therefore at risk of conceiving a child with that disease. Such knowledge – that one can be a carrier of genetic disease – can have reproductive implications. Technological advancement has recently made possible PECS for many hundred genetic diseases in the general population, without previous indication, such as family history or belonging to a high-risk group (Holtkamp et al. 2017; Delatycki et al. 2020).

The practice of PECS creates new questions of importance for ethical reflection, such as: which norms and values are connected to 'carriership' and what responsibility is placed on 'a carrier' in a moral sense? In this paper I will present my results from an empirical bioethical study where I have examined 'carriership' from the theoretical perspective of biomedicalization (Clarke et al, 2003). The empirical material consisted of semi-structured interviews with Dutch PECS test specialists.

Drawing on my results I will present descriptions of different forms of responsibility in relation to the PECS test, for example views on 'moral carriership'. Furthermore, I will unpack a discrepancy within the discussion on PECS, namely that on the one hand, PECS aims at supporting and enhancing reproductive autonomy for the prospective parents, but on the other hand – at least to a certain extent – there is accusatory rhetoric vis-à-vis couples who would not choose to consider taking the PECS test. The latter position of inaction is accompanied with ideas of irresponsibility (Monteleone, 2020), and is framed in the context of a presumed notion that the couple could have prevented suffering.

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Life on the edge: is it still possible to rely on the criterion of brain death?

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The current criterion of death, namely that of whole brain death (WBD), was born to meet the needs of physicians faced with transplants of certain patients' vital organs.[1] But since Christiaan Barnard performed the first heart transplant there have been many changes within emergency medicine; changes that could make WBD necessary, but not sufficient, to declare an individual dead. If WBD criteria is widely accepted by the scientific community, it is important to remark that it has numerous critical aspects. First of all, this criteria is based on the interpretation of

death as an instant, while the death of an individual represents a process that already begins in life. Since death has become such a medicalized process that is has become chronic, some patients tend to exhibit behaviors that are inconsistent with the diagnosis of brain death, such as moving parts of the body on command.[2]
Some authors believe that the criterion of WBD is sufficient to declare an individual dead, because this kind of patients often go in cardiac arrest within a few days of diagnosis, even if they are attached to a life-support machine.[3] Actually, some case studies show that this does not happen in all cases.[4]According to others, the criterion of brain death is sufficient to declare an individual dead because patients in brain death state stop functioning as an 'integrated whole'.[5] But some data show that this kind of patients have integrated functions, such as fighting wounds and infections, maintaining body temperature or continuing a pregnancy.[6]
How to account for these controversial aspects today? Is it possible to safeguard the criterion of brain death in the face of these new data that medicine provides us? The text will focus on the analysis of the current criterion of brain death, showing its intrinsic limitations and it will explore some case studies of patients in WBD. Finally, the paper will attempt to answer a number of questions, including: what does life look like for us today? Is it possible to declare dead a patient who moves body parts on command? Do we have or are we an organism? The answer to these questions will make it possible to articulate a bioethical discourse on the issues of death and life, including some reflections based on phenomenology and philosophy of mind.

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Method and 'The Problem of the Criterion' in Specific Cases of Bioethical Moral Knowledge

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Since at least the time of Descartes, philosophers have been in search of a "method" for their discipline. This includes a method for specifying what we can know, including what we can know in the realm of ethics and bioethics. Roderick Chisholm's in his "The Problem of the Criterion" presents a trilemma regarding the possibility of epistemology: methodism (using a method and criterion to sort out what we know from what we don't know), skepticism (giving up on the project of knowledge altogether), or particularism (starting from actual cases of knowledge to build an account or theory of knowledge).
Chisholm argues against both methodism and skepticism, and he argues in favor of particularism.

In this paper, Chisholm's trilemma (methodism, or skepticism, or particularism) will be applied to moral knowledge in the field of bioethics. This paper has four parts.
First, I present a brief sketch of Chisholm's trilemma and show how this trilemma is necessarily faced by anyone engaging in the field of bioethics. All bioethicists must resolve this trilemma.
Second, I argue with Chisholm that methodism and skepticism both face greater intellectual problems than particularism.
Third, I offer a "personalist" defense of particularism based on two routes to moral knowledge: the convertibility of being and goodness, and the nature of human persons as an ontological ground for moral knowledge in bioethics.
Fourth, I consider how a personalist particularism in bioethical moral knowledge can be applied to actual moral dilemmas facing practitioners of bioethics in real world decision making.

Narratives of nurses on use of cultural values: suggestions for ethics education

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Background: Ethics education is imperative in preparing the caring professions in healthcare. A range of literature cites numerous approaches to teaching ethics, and most emphasize the fusion of external values, directions, norms, and rules in developing the ethical competence of professionals. As such, the focus is on adopting external authority and becoming proceduralist in being moral. Although debates on using individual cultural values in ethics education have prevailed, the momentum regarding this critical aspect of human existence is not picking up. These values inspire our attitudes and are the basis for evaluating behaviours, events or objects as either good or bad, desirable or undesirable. Even though concerns regarding moral relativism have become an issue in ethics education and practice, there must be ways of using these values to strengthen the self-expressive aspect of ethics and its social presentation. In considering the usage, some authors suggest that cultural values should be given a prima facie stance and some adjudication where conflicts arise.
Purpose: The purpose of the research was to explore newly qualified nurses' experiences regarding applying their ethical knowledge on the basis that their understanding of ethics is still fresh from the training institution. And based on the results, the presentation focuses on the strategies and practices that may be employed in incorporating cultural values in teaching applied ethics.
Methodology: This presentation emerged from the empirical study using a qualitative research approach. Data was collected through in-depth interviews with newly qualified nursing students regarding their experiences applying ethical knowledge in their nursing practices. The transcripts were analyzed using interpretative content analysis.
Findings: The results revealed that participants relied on values and beliefs that formed a united self in respecting the dignity and the fundamental rights of others.
Conclusion: Therefore, the researchers recommend strategies for identifying and incorporating these values in ethics training and assessing these through reflections in practice.

Feminist Methods: A Missing Debate in the Methodological Bioethical Discourses

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Numerous epistemological and methodological approaches to questions in bioethics and philosophy of medicine exist. Most of them are well researched with an ongoing debate about their relationships and benefits. These include for example empirical bioethics, phenomenological ethics, analytic approaches and even emerging fields such as experimental or digital bioethics. Remarkably, feminist approaches received limited attention in the German-speaking medical ethical discourse so far. Against the backdrop of this "feminist gap", the following questions arise: what are feminist methods? Why are they rarely debated and what benefit could they provide in the field of bioethics and philosophy of medicine?
Outside of German-speaking medical ethics, for example in social sciences, critical theory or feminist philosophy/bioethics, there are lively international debates on feminist methodologies. These cover for example stand-point-theory, situated knowledges, intersectionality or relationality. By transferring the insights of these epistemological and methodological discussions into German-speaking medical ethical discourses the above-mentioned "feminist gap" may be filled.
We suggest that feminist research shares certain characteristics, such as context-sensitivity, intersectionality or attentiveness to the power of epistemologies rather than using a single method. Furthermore, we will investigate ways in which such a feminist research framework can be fruitful for different research designs and applied to various bioethical topics. For example, digital developments in medicine, such as implementation of AI-based systems and Big Data processing, pose their own discrimination risks. Therefore, we will use them to illustrate how feminist research approaches can help to address and analyze these emergent problems. Based on this example, we will conclude by showing the implications of a feminist research ethics for research in the field of bioethics and philosophy of medicine.

The Values-Based Consent Model: an empirical foundation

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With the rise of medical AI and digital data research, the need for electronic health record (EHR) reuse grows rapidly. It is the task of modern informed consent (IC) models to enable this process with feasible administrative and economic burdens while, at the same time, respect multiple individual and social values. There is a number of contemporary IC models for EHR reuse that offer attractive solutions to the practical problems that come along with data acquisition, processing, and analysis. However, all of those models have been criticised either because they turned out to be still administrative burdensome, or because they did not sufficiently satisfy the ethical purpose an IC is meant to serve. To tackle these issues we developed a new IC model – the value-based consent (VBC). Similar to the meta-consent model by Ploug and Holm (2016), it enables users to give different types of consent for different pre-defined categories of EHR research. What is new is the societal-centric approach to identify the right depth of each research category that is needed for each user to express their moral values adequately. For example, some research candidates genuinely belief that it is important to support every aspect of medical research, while others belief that research with human DNA is sinful. Some belief that it is a civic duty to enable the government to reuse EHR for purposes they sees fit, while others belief that it is more democratic to be able to react to political scandals

by denying IC for certain projects. Which exact consent options and research categories need to be available for users to express personal and social values sufficiently is an empirical question that we are going to answer with a mixed method study. The study includes semi-structured patient interviews (N=20) on all aspects of medical data research and moral values. The results of the interviews are verified in an online survey with members of a German institution, that is known for their support for strict data privacy policies (N=123). The participant selection ensures that the identified research categories even correspond to the value pattern of particularly critical users. The study identifies the right depth and density of research categories in the IC process and it highlights the advantages of the VBC compared to established IC models. The VBC enables researchers to analyse, match, and reuse EHR with a variety of methods without either having to ask for a new IC every step of the way, or scaring away potential research candidates with broad consent structures.

What kind of moral expertise is required for doing clinical ethics?

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Starting with the rise of Clinical Ethics Comitees (CEC) in North America in the late 1960s, CECs became a well-established institution within Health Care Services in many parts of the world in recent decades. Their overall aim is to support health care providers in coping with difficult moral issues that arise in clinical practice. The main emphasis seems to be clearly on ethical case consultations as the perceived main task of CECs. Upon request from the ward, a multi-professional team, accompanied by a moderator from the CEC, discusses the ethical questions regarding the case of an individual patient in a structured manner with the aim of arriving at the ethically most justifiable decision. Ideally, the moderators are trained according to existing standards and offer a structure for the discussion that enables the persons involved to present ethical evaluations and their justifications in the discussion and to weigh them against each other. In many cases, established discussion guidelines or models of clinical ethics consultation are used, which provide a framework for the discussion.
With the institutionalization and professionalization of clinical ethics, the question if and what kind of moral expertise these moderators (or consultants) do or should possess arose. Consultants aiming to professionalize should be able to articulate a special set of knowledge, skills or expertise that non-professionals in clinical ethics do not (regularly) possess. Apart from clinical ethics, the existence and nature of moral expertise has been a hotly debated topic in ethics and bioethics in general. In these general discussions many authors distinguish between narrow and broad moral expertise. Narrowly understood “moral expertise assumes an enhanced ability to analyze, understand, and conceptualize moral problems. Broad moral expertise encompasses the narrow version, and further assumes enhanced ability to know what is morally right” (Niv/Sulitzeanu-Kenan 2022). What position one holds if moral expertise exists in its broad or narrow understanding or not at all is mainly a question of meta-ethical beliefs (is there a kind of “truth” in ethics? What is moral reasoning? Is moral reasoning “just” applying moral norms? etc.).
While these general discussions and meta-ethical reflections are important, we argue that these common understandings of moral expertise are cognitively biased – at least when it comes to clinical ethics. Moral expertise in clinical ethics consultations is not fully captured by armchair theorizing but unfolds in the interpersonal application of ethical deliberation with the other participants. So every account of expertise regarding clinical ethics consultations must be able to incorporate the interpersonal character of it as a practice (a kind of doing ethics). Even authors like Rasmussen (2016) that differentiate between an (ideally constructed) universal

ethics expertise and expertise in clinical ethics consultations can't fully do justice to ethics consultations as a joint action and stick too much to a traditional model of individual armchair ethical decision-making. We ask what a concept of moral expertise could look like that does incorporate aspects of jointly doing clinical ethics.

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The emergence of Mediterranean Bioethics: principal ideas and protagonists

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If we consider bioethics a discipline reflecting culturally-rooted values, we much better understand the necessity of appearance of regional variations of bioethics. Due to diversity in intellectual heritage, traditionally present in the Mediterranean basin, Mediterranean Bioethics seems particularly promising with respect to its originality.
In this work, analysed are primarily ideas by Alasdair MacIntyre (b. 1929), the Scottish-American political and moral philosopher, Diego Gracia Guillén (b. 1941), philosopher and psychiatrist from the Madrid Complutense University, and the Sicilian priest and poet Salvatore Privitera (1945-2004) – which we believe have shaped the fundaments of Mediterranean Bioethics in the late 20th century. We comment on how original those concepts are with respect to the mainstream "Georgetown" bioethics/biomedical ethics, and how close they stand to the ideas of the two "fathers" of bioethics – the German theologian and teacher Fritz Jahr (1985-1953) and the Wisconsin cancer biochemist Van Rensselaer Potter (1911-2001). Since bioethical ideas develop quite dynamically, we trace a few more concepts fitting well into the Mediterranean Bioethics basic „paradigm," including those by Menico Torchio, Luisella Battaglia, José María García Gómez-Heras, the German-Croatian school of „Integrative Biooethics," etc.
We conclude that the idea of a Mediterranean Bioethics, even if itself present in several variations, offers an original framework for bioethical reasoning based on and oriented to specific autochthonous values and problems.

Brinkmann's Socratic dialogue as an empirical bioethics approach

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Empirical ethics is the integration of empirical data with theoretical reflection based in moral theory. (Molewijk et al. 2004) We suggest an approach derived from Brinkmann's (2007) method of epistemic interviewing based in Socratic dialogue. This approach shares two elements with several other empirical ethics approaches: (1) the aim is to seek knowledge through questions and justifications, not to map and analyse opinions; and (2) the researcher is a participant in the dialogue rather than mere "spectator". (Skjervheim 1996) Arguably, empirical ethics seeks to reinvent social science data gathering to help answering normative questions. In their review of empirical bioethics research, Davies and colleagues place different

methods on a continuum from Dialogical approaches aiming for consensus, based in a joint analysis by facilitators and participants, and Consultative approaches, where data is analysed and concluded by the researchers independently of the data collection. (Davies et al. 2015) Socratic dialogue is closest to the Dialogical approaches, but unlike these it is not consensus-oriented, but "antagonistic", driven forth by challenges and criticisms between participants. Consensus is not a goal of the concrete dialogue, but a regulative idea guiding the inquiry. (Habermas 1997)
The researcher takes the role of participant, which means engaging in a process of reciprocal challenges and understandings, avoiding the superior role of the spectator. Hence, Socratic dialogue is not best understood as empirical data integrated with normative reflection. The participants take part in the philosophical work together with the researcher, bridging the gap between the empirical and the systematic normative analysis from the outset. The empirical work is the normative reflection. It is questionable whether it is appropriate to call the transcriptions from the dialogue "empirical data" at all. With this approach the data has a different character from the opinions and arguments gathered in traditional social science research.
But the method is not completed in the dialogue. As in Consultative approaches, there is a need for an independent analysis and structuring of the empirical material. Since the goal of the method is to develop the argumentative potential in dialogues, transcriptions should not be handled as empirical data, but as texts aiming for knowledge. That is, the researcher reads them looking for themes, arguments and viewpoints like philosophers do when engaging with any text. Although this methodology constitutes a form of empirical engagement, it is closer to the way philosophers use literary texts and other non-academic written material. (Nussbaum 1990; Hämälainen 2009) Thus, Socratic dialogue is related to regarding interviews and focus groups as "'encounters with experience' and using those encounters to inform one's philosophy". (Ives 2008, 2) Accordingly, this is not merely a method for seeking knowledge in normative matters, but also an arena for self-reflexivity, a form of reflective empiricism. (Winther 2022)
The potential of the approach will be illustrated with issues from contemporary debates in bioethics.

Ethical issues raised by the potential use of predictive tools for the risk of severe mental disorders: a scoping review.

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Over the last decade, there has been considerable development in precision psychiatry, especially in the development of prediction tools that can be used for early prediction of the risk of severe mental disorders running in the family such as schizophrenia, depression, bipolar disorder, etc. Although the clinical efficiency of those tools is still unclear it is crucial to consider the potential ethical and social consequences of their clinical use before these tools are used in practice. The literature on this issue is rapidly growing and represents input from scholars from different fields - psychiatrists, bioethicists etc. However, to our knowledge, nobody has produced a systematic review addressing these questions. Therefore, the present study aims to bridge the gap. As the literature we have to review includes both empirical and non-empirical studies we decided to conduct a scoping review. The research question we are going to address is: What are the ethical and social issues raised by the potential use of predictive tools for the risk of severe mental disorders that are identified in the existing empirical and theoretical literature? We are going to conduct the search using the relevant search words in three databases - Web of Science, Scopus and PsychINFO. After this, we will

screen the papers according to the inclusion and exclusion criteria, and then by applying qualitative content analysis we will identify ethical issues addressed in the literature. In the conference paper we are going to present the preliminary results of this study.
The project "Running in the FAMILY – Understanding and predicting the intergenerational transmission of mental illness" leading to this abstract has received funding from the EU Horizon programme under grant agreement No. 101057529.

The death of an organism and death as the loss of moral status. Does the organismal superposition problem challenge the first, while nihilism challenges the second?
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According to the mainstream bioethical stance, death constitutes the termination of an organism. In this article, I argue that such an understanding of death is inappropriate in the usual context of determining death, since it also has a social bearing. There are two reasons to justify this argument. First, the mainstream bioethical definition generates an organismal superposition challenge, according to which a given patient in a single physiological state might be both alive and dead, like Schrödinger's cat. Therefore, there is no clear answer as to whether organ retrieval from a brain-dead patient is an act of killing or not. Second, when combined with the dead donor rule, the mainstream position in the definition of death might lead to ethically unacceptable verdicts, since there is a discrepancy between terminating an organism and depriving someone of moral status.

Aristotelian medical virtues, Christian medical virtues, and end-of-life decision making
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In 1847 the AMA advised physicians that they have a "sacred duty" to "minister...hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which often disturb the tranquillity of the most resigned in their last moments" (Code of Ethics of the American Medical Association. Philadelphia: Collins Printers, 1847, Chapter 1, Article 1.4, p. 9). This was directed not only at Christian physicians but at all American physicians, who were encouraged to instil hope in dying patients, whether or not the patient had any religious affiliation. The virtue of medical beneficence is no longer understood to include a preparedness to instil hope in the dying – doctors have learned from experience that this does not serve patients' best interests. Both secular and Christian accounts of medical virtues have thus become more evidence-based, and have developed more inclusive approaches to the best interests of patients generally. Aristotelian accounts of medical virtues emphasise the importance of doctors developing practical wisdom, in fine-tuning virtuous dispositions to hit their targets. Such accounts are more empirically informed than previously, in drawing on empirical studies of factors – like the prevalence of certain cognitive biases in clinical practice – that divert virtuous dispositions from their targets. How might Christian accounts of medical virtues draw constructively on such studies? And, might Aristotelian accounts of medical virtues learn important lessons from Christian approaches to medical virtues? In this paper I critically compare these two approaches to medical virtues, in the context of end-of-life decision making.

A Non-western approach to address the current dualisms in Synthetic Biology

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Synthetic Biology (SynBio) is a promising new field in science that covers a variety of areas of research. It is an umbrella term for various research areas that apply engineering principles in science. The technology claims to provide solutions to many global problems, from reducing carbon footprint and providing more sustainable forms of fuel to addressing food and medicine shortages. However, as with any newly developing technology, all the benefits it can provide are combined with certain risks. SynBio, like many others, is a perfect example of a technology with a dual-use dilemma. However, SynBio also raises new ethical and social concerns never seen with any technology before.

SynBio incorporates engineering principles with biology to create or alter existing life forms and achieve the desired products through a bottom-up approach. While this gives rise to the usual biosafety and biosecurity concerns, blurring the distinction between life and non-life raises philosophical concerns. Some of these concerns are questioning human's role in creation, the moral status of the newly created entities, life vs. machine, natural vs. unnatural, etc. In current ethical literature on Synthetic biology, the distinction between life and non-life, biology and technology, and natural and unnatural carry normative weight. The fact that synthetic biology challenges these distinctions is considered ethically relevant.

Through this presentation, I will use a non-dualistic approach or framework to find a possible way to address these philosophical concerns. I will use ancient Indian philosophy (Hinduism) to situate and attend to these philosophical concerns through the Indian philosophical framework. Ancient Indian philosophy (Hinduism) is an example of biocentrism in which though a human being is thought to be endowed with a consciousness that exceeds the consciousness of other species, he is not considered superior to them. Hinduism has a holistic approach to life and nature in which a human being is an integral part of an organic whole, and the natural forces are considered sacred. Hinduism's spiritual, metaphysical view has a holistic approach to all of nature and life where human life, like every other life on earth, forms part of the web of existence. Together with the material elements, human and nonhuman species are indissolubly linked in an organic whole, thereby remaining non-dualistic in their approach. Using this framework, I would like to explore if a non-dualistic perspective can help us take a different path to address the current ethical and philosophical concerns in SynBio.

Rethinking the "bridge" of Bioethics, between Medicine and Humanities

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Few authors (e.g. R. A. McCormick, W. Reich) have recognized a "malaise of bioethics", with the need of a more dynamic interface between medicine and humanities, rediscovering a narrative approach, which includes the historical context, the symbolic dimensions, and the contributions of literature, cinema, and paintings.
Placing the persons at the center to promote their health, treat their diseases, and follow their rehabilitation pathways increasingly calls for a close collaboration among science, medicine, and humanities. In fact, fine arts and human studies, as well as social sciences, are instrumental in understanding the human dimension of both the sick person and the caregiver (doctor, nurse, family).

The perspective of a multidisciplinary dialogue that needs to be resumed and promoted, helps erect a "bridge" among different types of knowledge, enabling a better acknowledgement of the realities of treatment, that is, medicine in all its expressions.
It is possible to improve this approach, with these declinations: Bridge, Relationship, Responsibility, Socio-cultural Context.
The recent Covid-19 pandemic has also produced narratives, artistic forms, and musical manifestations that have promoted a vision of what is happening.
The lockdown, social distancing, loneliness, therapies, and vaccines expressed the fears, hopes, difficulties, and responsibilities experienced in the spring of 2020.
This recalls the fragility and vulnerability of our human condition. We thought and deceived ourselves into believing that we were omnipotent and immortal; however, we found ourselves powerless and mortal, with multiple fears and spiritual and psychological crises, seeking renewed trust and hope.
Medical Humanities should be part of the identity and purposes of medicine in a structured and continuous way, only so a true person-to- person relationship can be achieved. This could help to prevent forms of burnout and moral distress. In fact, the presence of medical humanities to express and process emotions and responsibility can help manage the psychological involvement and ethical commitment in more balanced and healthy way. All this should promote a good relationship with the patient, a good relationship with oneself as caregiver, and a good relationship with health institutions.
Bioethics could find new perspective and offer contributions to define health, care, meaning of all these experiences. Involving the whole social reality to define the concept of health, care, justice, and solidarity and moral responsibility of all subjects involved.
It is precisely about the urgency to reconstruct a necessary and forward-looking bridge between different life sciences and arts, so that medicine can find a “soul” and cure-care every person as a whole.

Efforts against hype stuck in the logic of overpromising? The role of bioethics in stem cell and organoid hype

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Bioethicists routinely face the challenge of avoiding hype in their analysis and discussion of recent biomedical and biotechnological developments. This paper critically analyzes the role of ethicists in the hype of stem cell research and organoid technology. I’ll argue that, notwithstanding increased awareness of the problem of hype and efforts to counteract it, bioethical approaches and methods as well as problematic assumptions about science and technology development contribute to difficulties in overcoming the logic of overpromising in ethical debates on stem cell and organoid research.
Stem cell research is a suitable case study for exploring the role and longevity of hype because of its explicit discussion and efforts to work against it both from within the scientific community as well as from ethicists, social scientists and journalists. Stem cell science communication has been criticized for fueling hype (Caulfield et al. 2016) and more cautious communication strategies have been called for and framed as part of scientific integrity in the 2016 update of the Guidelines of the International Society for Stem Cell Research (ISSCR). Nevertheless, certain assumptions about the state of research and the therapeutic applicability of stem cells seem to have become entrenched within public perception. This is at least indicated by the constantly high demand for unproven stem cell therapies and the massive increase in the number of clinics offering them in recent years (Turner 2021). While important sources of hype and

misrepresentation of stem cell research lie in the commercial sector with its direct-to-consumer advertising strategies (Petersen et al. 2017), in science funding and promise-requirement cycles (Van Lente 1993) as well as the relationship of science and the media (Nelkin 1987), also ethical discourse itself played and still plays a role in sustaining hype. Due to the openness of the research process, it is of course difficult to draw a clear line between exaggerated promises or hype on the one hand and realistic hopes and expectations of future developments on the other. However, the recent organoid discourse, though actively trying to avoid hype, tends to fall prey to the logic of overpromising as well. Lessons were learned from the stem cell debate mostly in terms of avoiding overt hype, but not in terms of reflecting ethicists' own attitude towards the life sciences and the role of bioethical approaches and ways of thematization that lead to indirect hype and narrow views of science, often separating it from its societal conditions and political dimensions. The upshot is that hype cannot be avoided by means of more cautious communication alone. Instead, the relationship of ethics and science, socio-technical imaginaries (Jasanoff & Kim 2015), (often implicit) assumptions about science and society and the sociopolitical role of bioethics itself need to be critically analyzed and partly reconfigured.

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However she wants a child, with whomever she wants a child: against a-priori age limits for men in reproductive care

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The average age at which people have children has been on the rise for decades now. At the same time, almost all countries and fertility clinics impose age limits on women who want to become pregnant through Assisted Reproduction Technologies (ART). Although the wide variety among these age limits can be rather question-begging, they nonetheless help to avoid futile treatment, secure an efficient allocation of public funds and avoid serious harm to the future child. Age limits for men however, are much less common while it is becoming increasingly clear that the age of the father is also of moral relevance. Yet to what extent remains a point of debate. This contribution starts from the principle of reproductive autonomy and an according positive conditional right to receive ART. Posing the question as to whether there are strong-enough arguments to also impose age limits on men, it subsequently considers

an array of mostly consequential arguments in favour of age limits for men of (very) advanced age. After all, as men get older, their sperm quality gradually decreases, leading to an increased chance of a variety of syndromes, future health risks and birth defects in the offspring. In addition to that, a father of (very) advanced age might have a negative influence on the (mental) wellbeing of the child. Finally, with regards to gender equality, a significantly older father will most probably lead to an unequal division of parental tasks in the household as he will sooner or later become in need of care himself while the child has not matured yet. Despite these arguments, we will nevertheless end up arguing that they are not convincing enough to justify a priori age limits that trump the reproductive autonomy of both the man and the woman: The risks are not high enough, the idea that an old father causes significant harm to the wellbeing of the child is not backed-up by evidence and it is up to the couple to decide what division of responsibilities they are willing to accept. Also, the couple can arrange a support network. We reinforce our position by drawing a comparison between the case of a 39-year-old woman who wants to become a single mother via a sperm donor on the one hand, and on the other hand the same woman who wants to have a child with a 64-year-old man who she loves and who is willing to care for the child as long as he is able to. Although the ethical case for single motherhood has been made, a scenario where a father of (very) advanced age is involved still seems to be condemned. We conclude that a priori age limits for men are always unwarranted and that there should be case-by-case assessments instead. This would properly respect the reproductive autonomy of the man and especially of the woman.

Inclusion in clinical research: cross-sectional study assessing potential barriers to informed consent in randomized controlled trials published in top general and internal medical journals

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Objective: Racial and ethnic minority groups are underrepresented in clinical research. Racially diverse individuals that speak languages other than English or have limited proficiency may be hindered from participation in randomized clinical trials (RCTs) through eligibility criteria. This study sought to assess English language requirements for enrollment in registered and published RCTs.
Design: In a cross-sectional design, we searched for RCTs in high-impact medical journals on May 4, 2022, with at least one US site comparing heart disease, stroke, cancer, influenza, respiratory disease, diabetes, HIV/AIDS, and COVID-19 drug interventions with ClinicalTrials.gov registration. We assessed whether English or another language was required for enrollment in eligibility criteria in protocols and ClinicalTrials.gov records. The primary outcome was frequency of RCTs with English language requirements in eligibility criteria by disease and funder. Secondary outcomes were readability of eligibility criteria and reporting of race as a demographic variable. Readability comprised Flesch-Kincaid grade (FKG) level (ranges from grades 0 to 18 [college graduate]) and Gunning-Fog (GF) (ranges from grades 0 to 20 [college graduate]), where lower grades correspond to easier readability.
Results: A total of 39 of 6394 RCTs. Trials mostly studied COVID-19 (n=18/39, 46%) and were industry-funded (n=23/39, 59%). Eligibility criteria in publications or ClinicalTrials.gov made no explicit statements about English or any other language required for enrollment. The lack of explicit statements about languages required for enrollment was common in both industry (n=17/39, 44%) and non-industry funded (n=8/39, 21%) in protocols. Ten (26%) industry-funded and non-industry funded trials (both n=5/39, 13%) provided non-English

languages. Participant race was reported in 37 (95%) articles and ClinicalTrials.gov. There were 17/39 (44%) RCTs with at least one difference in the reporting of race in articles and ClinicalTrials.gov. Eligibility criteria in protocols had a median (IQR) FKG of 11.5 (10.7-13.0) and GF of 13.0 (11.7-14.5) and in ClinicalTrials.gov, the median (IQR) FKG was 13.0 (11.0-14.0) and GF was 13.7 (IQR 11.7-14.7). In protocols, readability did not differ by funder (FKG for non-industry; 12.1 (11.4-13.3) vs. FKG for industry; 11.0 (10.3-12.6) and GF for non-industry; 13.4 (12.2-14.7) vs. GF for industry; 12.90 (11.6-14.5)), P=0.092 and, (P=0.567), respectively. In ClinicalTrials.gov, readability did not differ by funder (FKG for non-industry; 12.9 (11.7-13.9) vs. FKG for industry; 13.5 (10.7-14.6) and GF for non-industry; 14.5 (11.7-15.1) vs. GF for industry; 13.4 (12.2-15.7), P=0.575 and GF P=0.338, respectively.
Conclusions: There was low explicit reporting of required languages in eligibility criteria, and readability was low. Ethics committees and funders should obligate the inclusion of the explicit reporting of languages and high readability of information for participants. Accordingly, responsibility rests with ethics committees, funders, and trialists to conceive inclusive trials to strive toward health equity.

Capacity, Autonomy, and Risk: Reflecting on Asymmetries in Capacity to Consent and Capacity to Refuse
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There has recently been renewed interest in the question of whether we should understand standards of decision-making capacity (DMC) to be risk relative. Critics of risk-relative standards often highlight a puzzling asymmetry that it implies; a patient may have the requisite DMC to consent to a treatment that is in their best interests, whilst lacking the requisite DMC to refuse that same treatment, given the much higher risk that this would entail. Whilst some have argued that this asymmetry suggests that risk-relative standards are nonsensical, in this paper I defend a 'quality of evidence' view of such standards. I begin by outlining DMC's gate-keeping role in medical ethics, and identifying three key normative claims that undergird this role. I then explain how two competing theories of risk-relative standards, which I call the 'true capacity threshold view' and the 'cost of error' view, are incompatible with at least one of these claims. Drawing on Douglas' distinction between standards of 'true capacity' and standards invoked in the 'test' for capacity, I then outline my quality of evidence view. I explain how the view is compatible with all of the aforementioned normative claims, and the nature of the asymmetry between cases of consent and refusal that it implies. I conclude by defending the view from Wilks' suggestion that there is no meaningful distinction between standards of 'true capacity' and standards invoked in the 'test' for capacity.

What do bioethicists believe? The results of a survey to researchers in bioethics, medical ethics and philosophy of medicine
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What are the ethical views of researchers working in bioethicists and closely related fields? Is abortion morally permissible? Is commercial gamete donation ethically permissible? Should patients be allowed to refuse treatment that would be beneficial for them? At what age can a child refuse medical treatment to which her parents have consented? Is it ethical to use animals in biomedical research? Is there a moral obligation to be vaccinated? These are some of the 60

questions we asked of professional bioethicists. We divided the questions into seven themes, framed questions as statements and asked scholars to respond whether – and to what extent – they agree with the statements. The seven themes were: reproductive ethics, treating of patients, research ethics, human enhancement, public policy, sexuality and gender, and death and dying. We analyzed the responses received from a total of 200 researchers and documented the results. The analysis shows correlations among ethical views and between the ethical views and factors such as career stage, gender, the field of one's PhD, and religious belief. We present the results of the survey.

Empirical ethics of novel, emerging prognostic models in genetic neurodegenerative disease: a qualitative interview-study

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Novel biotechnologies are currently being developed that aim to predict the age of onset (AO), the disease severity, and the progression of disease symptoms (POD) of genetic, neurodegenerative diseases. Huntington Disease (HD) and Spinocerebellar Ataxia (SCA) are examples of autosomal dominant, adult onset and untreatable neurodegenerative diseases. Since the 1990s, individuals at risk for HD or SCA can seek predictive testing to learn whether they carry the mutated gene and get the disease in their lifetimes. Currently, we are heading towards a new situation: research consortia are developing a prognostic model that may provide an accurate prediction of the AO and POD. The value of AO and POD prediction can be threefold: 1. for personal use: to make decisions about (future) life plans and reproduction, 2. in clinical research settings: accurate prediction is needed for participation in clinical trials, and 3. in clinical care settings: to estimate the exact timing to start therapeutic interventions – assuming that, in the future, medical treatment becomes available.
The development of new predictive testing raises ethical, psychological, legal and societal questions. Do gene mutation carriers wish to learn predictive information about AO, disease severity, and POD? What will be the (perceived) impact on their well-being and their life decisions? Should clinical geneticists provide gene mutation carriers routinely with this information? Are gene mutation carriers required to learn AO and POD in order to participate in clinical trials and receive treatment? What are the societal consequences of knowing AO and POD information for carriers? Since onset prediction will often be based on data from different resources (eg., patient-derived data, biomarkers, neuro-imaging data) and on the use of artificial intelligence (AI) to process these data, ethical issues related to the trustworthiness, transparency and accuracy of AI will also be relevant.
In our study, we use a method of empirical bioethics, in the sense that empirical data are used to support normative ethical conclusions. We conducted a qualitative interview-study with recently tested mutation carriers of HD and SCA to learn their preferences and views on AO and POD prediction and to understand the expected impact on their well-being and personal decision-making. We aim to integrate those findings in a normative ethical analysis of the conditions necessary for responsible development and implementation of AO and POD prediction in research and clinical care. As Ives et al showed, there is a level of consensus on general standards for empirical bioethics (1). However, within this consensus different positions are still possible (e.g., integration of empirical and normative elements). Reflection on methodology therefore remains necessary to further develop the field of empirical bioethics.

In our presentation, we will present the findings of the interview study and by means of the standards of empirical bioethics of Ives et al, we will provide a reflection on the chosen methodology of and position on empirical bioethics for this study.

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Planetary Health: Ethical Implications for Health Care

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The Lancet Commission defines Planetary Health as "the achievement of the highest attainable standard of health, wellbeing, and equity worldwide through judicious attention to the human systems—political, economic, and social—that shape the future of humanity and the Earth's natural systems that define the safe environmental limits within which humanity can flourish." Put simply, planetary health is the health of human civilization and the state of the natural systems on which it depends. The moral ambitions of this idea are both great and limited. Great because it is clear that the state of planetary health is critical, and achieving the highest attainable standard of health and well-being globally is a long way off. Human health and well-being are threatened in many places, and those threats are very unevenly distributed. If the ideal of planetary health is embraced as a core value in medicine and health care, what are the ethical implications?
In this presentation we argue that within this ideal, the health of humans, animals, and nature are worthy of protection for their own sake. These values can reinforce each other, but they can also clash. We then formulate a general framework that provides some direction for ethical considerations. We next discuss implications of the ideal of planetary health for animal research, for sustainability of health care, and for global health and solidarity. A general conclusion is that planetary health places limits on health care, which further exacerbates dilemmas surrounding the sustainability of health care.

Transparency and authority concerns about the use of algorithmic ethical decision-making in health care

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In response to several recent proposals to utilize machine learning to automate ethics consultations in health care, we raise two problems—the transparency problem and the authority problem—for the prospect of having medical professionals rely on algorithms to provide ethical guidance in clinical matters. The first cause for concern is that, because these algorithmic recommendations would effectively function like black boxes, this approach seems to preclude the kind of transparency that would allow medical staff to explain and justify treatment decisions to patients, fellow practitioners, and those tasked with providing oversight of those recommendations. The other problem is that the kind of authority that would need to be given to the guidance issuing from these programs in order to do the work set out for them would mean that medical staff will lack the requisite capacity to set aside this guidance or provide any meaningful check against it in those cases when its recommendations are morally

problematic. Taken together, these concerns constitute a dilemma and provide sufficient reason to think that algorithms will not be suitable for replacing human beings in making ethics recommendations in health care.

Protecting the "inner citadel" in the age of neurotechnologies. An ethical analysis of the right to mental integrity

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Recent developments in neuroscience and neurotechnologies create unprecedented challenges to human identity, agency and basic human goods (López-Silva & Valera 2022). To address these challenges the concept of (moral and legal) "neurorights" have been developed (Ienca and Andorno 2017, 2021; Yuste et al. 2017). It refers to specific freedoms and entitlements of a person aimed at protecting and promoting her mental integrity, mental/cognitive liberty, metal privacy, and equality. Although neurorights have gained huge attention in media and political arena, they are "still in a germinal stage of theoretical maturity" (Ienca 2021: 6). There is no consensus on a list of proposed neurorights, their names, conceptual boundaries, normative justification and status, or their application (cf. Bublitz 2022: 6; Borbón and Borbón 2021; Ienca and Adorno 2017, 2021; Yuste et al. 2021)

This presentation focuses on a neuroright that has rarely been a subject of an in-depth scholarly inquiry, namely the right to mental integrity. While there is a general agreement on the moral significance of the right to mental integrity, there is still a substantial disagreement, among those few scholars who have explored it, over how the right should be defined and interpreted (Ienca and Andorno 2017, 2021; Lavazza 2018, Douglas and Forsberg 2021; Fuselli 2020; Hildt 2022). For example, Ienca and Andorno (2017, 2021) define the right narrowly as the right to be protected from illicit and harmful manipulations of cerebral and mental activity. In contrast, Lavazza defines it broader as "the individual's mastery of his mental states and his brain data so that, without his consent, no one can read, spread, or alter such states and data in order to condition the individual in any way" (2018: 4). The debate is still open. Further clarification and exploration of the right are needed

The aim of this paper is twofold. Firstly, to provide a conceptual analysis of the right of mental integrity, and of its relation to other values and rights affected by developments in neuroscience and neurotechnologies, such as mental/cognitive liberty, mental/personal identity, and mental privacy. Secondly, to discuss a normative role of the right to mental integrity in the context of existing human rights and the proposed neurorights.

I will argue that the right to mental integrity should be understood as both a negative right that protects person's (brain and) mind against interventions she has not consent to, and a more powerful and rich positive right to govern one's mental states in accordance with one's understanding of being whole, sound and complete; in a line with a person's vision of 'true self' or 'authentic self'. As such, the right should be viewed as a core value of neuroethics and neurolaw providing philosophical grounds and normative justifications for protecting mental/cognitive liberty, mental/personal identity, and mental privacy.

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Fabricating Humans: Ethical, Legal and Social Issues of 3D Organ Bioprinting

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3D bioprinting of tissues and prototype organs is one of the most promising areas of biotechnology. Now entering the stage of “evangelism” (1), 3d bioprinting looks at the final goal to make available organs for succesfull tranpslants in humans. However, a number of ethical, legal and social issues stem from this new technology. The main issues at stake cover new ethical horizons as well as classical issues like confidentiality, informed consent, intellectual property rights (2). The starting point of the latter is the source from which bioprinted organs and tissues are developed. In case of allogenic stem cells, the ethical issues cover exspecially the need for alternative sources to embryonic cells which are not currently authorised for therapeutic or research use in many countries due to ethical and legal limitations. In case of autologus stem cells, ethical issues are arisen from safety reasons (such as the risk of tumorigenicity), potential cell lines immortalization (when primitive stem lines survive to the recipient), or for the lost of alternative better treatments (once the organ is transplanted and can not be longer removed from the patient body). A multy-layered consent form should be used to give the patients the chance to consent to some research protocols only or to opt for selected therapuetic tretaments. Furthemore, confidentiality should be guaranteed to the patients by securing the use of anonymed materials and data. Specific regulations should be developed worldwide in order to govern 3d organ bioprionting which is currently regulated in different ways (3).

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The dialogical thinking as an ethical theory between meta-ethics and applied ethics

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In contemporary philosophical thinking the dialogical perspective is decisive with the contribution of Christian and Jewish thinker as Martin Buber, Franz Rosenzweig, Ferdinand Ebner, Emmanuel Lévinas and Romano Guardini. These thinkers, writing after First World War one century ago, described the dialogue related to the other/Other, with a decisive contribution of language, with a central role of community and society, in an open transcendence and with a continuous integration of the epistemological dimension. The paper will focus on three main steps:
The first one is about the dialogical thinking as fundamental ethics, one of the contemporary philosophical theories in connection with other philosophical theories; we will focus on the dialogue in its relation with the theory of justice, the utilitarianism, the ethics of virtues, the ethics of care and responsibility, with theory of principles and the ethics of self-determination. The second one is the possibility of using dialogue as an instrument for intersectionality between different disciplines; in the age of "iper-specialization" the dialogue is a bridge not only between ethics and medicine but also between the different discipline in science and medicine; in this sense dialogue isn't only a method for thinking about others but also a method for thinking with others. The third one is the importance of dialogue in the applied forms of bioethics, for example in the life of ethical committees or in caregiver-patient relation. The dialogue is here a decisive form of argumentation.
In these three steps we can see the dialogue not only as an instrument for descriptive and normative ethics, but in a deep connection with fundamental ethics and also with ethics of education. Bioethics is dialogical inside but expresses outside this dialogical root in the connection with society and new generations as educational ethics, preventive and predictive. In this direction ethics has also a "parenethical" (exhortative) function, indicating the urgencies of this time and the possible way towards future.

From the Biopolitics of Reproduction to the Bioethics of Reproduction

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Eugenics, racial hygiene, marriage laws, anti-natalism, sterilization, pronatalism and anti-abortion campaigns: these notions all represent various forms of biopolitical interventions that may differ in their level of coercion and discriminatory effect but all place reproduction and family planning in the center of biopolitics. In many state-socialist countries population politics during the cold war period was regarded as a means of compelling citizen subjects to reproduce the sufficient labor force and by this exercising control over the most private sphere of the individual. Despite the various ethical dilemmas, reproduction was rarely seen through the lens of reproductive ethics. While homogenization efforts within the state socialist period helped to reduce racial biases, some hidden patterns of eugenic thinking still remained in the field of medicine. Sterilization practices and access to abortion had often hidden eugenic concerns. Socialist population control gradually fostered pronatalism and the commodification of reproduction transformed biopolitics from eugenic control to the control over women's bodies.

Reproductive ethics in the domain of old and new technologies is still a contested field. Human rights norms are capable of addressing some issues of discrimination and offer some degree of reproductive autonomy and privacy protection but do not cover specific bioethical questions.

Furthermore, the variety of legal solutions demonstrates that there are many ethical concerns around reproduction. While the law predominantly serves the actual consensus on biopolitics, reproductive ethics should address issues, such as informing partners about hereditary conditions within the family, the limits of reproductive self-expression, parental choices, desire for enhancement, sustainability, etc. Should reproduction beyond the genetic bond be respected? Should right to genetic affinity be acknowledged? Are there rights to genetic identity? To what extent can one accept and protect genetic and reproductive privacy? In the case of preimplantation genetic choices how should one assess the rights of the child? And in general, how would bioethics of reproduction look like once biopolitics were put aside? Bioethical conventions because of the biopolitical issues at stake, (especially in the field of abortion), have refrained from taking a position even in those reproductive matters where the simple norm of informed consent would provide an answer. These hesitations come mainly from the restrains by biopolitical thinking. The presentation would address the evolution of bioethics beyond biopolitics in the field of human reproduction by applying historical analysis and feminist legal theory.

Methodological Mistakes in the Metaphysics of Harm

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The vast majority of clinical decisions, whether made by the healthcare provider or the clinical ethicist, operationalize the concept of harm in the appraisal of risk and benefit; it is for this reason that Inman's aphoristic interpretation of Hippocrates—the famous "first, do no harm"—remains so influential in medicine. The extent to which both clinical practice and bioethics rely on the concept of harm, however, starkly contrasts with our limited philosophical understanding of what harm is: despite fifty years of debate, no single metaphysics of harm has withstood rigorous analysis, and the vast majority of clinical decisions remain dependent on a concept which we struggle to understand.

My intention here is to demonstrate that our continued metaphysical ignorance is not the result of inadequate theorizing, but of faulty methodology. We begin with a discussion of the two canonical schools of thought on the question at hand: Comparitivism, which holds that facts about harm to being A at time t supervene on comparisons to A either (i) in other possible worlds or (ii) at times other than t, and non-Comparitivism, which holds that facts about harm to A at t merely supervene on facts inherent to t. Having provided this brief exposition, I turn to analyze the methodology which is used to develop these different theories.

The Comparativist and non-Comparativist schools, I argue, are rendered inadequate by a two-pronged methodological failure. First, I argue that most canonical theories—including those advanced by Joel Feinberg, Judith Jarvis Thomson, Michael Rabenberg, and Elizabeth Harman—employ approaches which, due to their reliance on intuition, obscure the role which our values and beliefs play in our understanding of harm. This methodological blind-spot, I argue, has rendered these theories unable to account for the ways in which harm seems to be deeply personal and individualized: how, for example, an event which may be quite harmful to you may not be harmful to me. Second, I argue that the foundational dichotomy which underlies this dialectic is a false dichotomy. I motivate this claim by arguing for the existence of both comparative and non-comparative harms: while most harms, such as the loss of some good or the inability to attain some future end, are necessarily comparative, a number of clinically significant harms—including those involving the violation of ones' rights—are harmful in and of themselves, and are thereby harmful non-comparatively. I conclude, then, that so long as this

dialectic respects the traditional Comparativist/non-Comparativist dichotomy, it will never produce a theory which accounts for all relevant forms of harm.
The two-pronged failure of the Comparativist and non-Comparativist schools allows us to explicitly state two desiderata which have yet to be met by current theories: (a) that a theory should be able to account for the ways in which harm seems to be personal and individualized, and (b) that a theory should be able to account for both comparative and non-comparative harms. To meet these desiderata, further work must be done.

Interpretation and specification in bioethics: Never out of style?
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The canonical portrayal of bioethics' origins is that of a renewed interest in applied ethics, resulting from, on the one hand, an array of technological developments requiring practical solutions and, on the other hand, a dissatisfaction with metaethical theorizing. To an important degree, this is illustrated by the still dominant principlist account developed by Beauchamp and Childress, with its focus on four non-hierarchical principles and minimal reference to moral theory for justificatory purposes. Against this background, Toulmin's catchphrase that 'medicine saved the life of ethics' has long seemed an apt epitome of this story, but current debates in bioethics raise questions whether it may now be philosophical theory's turn – possibly in the form of metaethics –to step in to save the life of bioethics. In response to emerging technologies – ranging from developments in genome editing to increased automation and prediction in delivery of care – scholars have flagged that entrenched bioethical principles may be unfit to adequately deal with the moral challenges of the future. Of such technologies is spoken in terms of their 'disruptive potential', which – albeit still elusive – minimally illustrates the doubts about how these developments might transform not only moral views but also fundamental concepts and principles like 'respect for autonomy' (which, indeed, has been a relatively popular target). In this contribution, I argue that such conceptual challenges to deal with emerging, and possibly disruptive technologies, need not be disruptive in a conceptual sense. Rather, if we appreciate the slim metaethical – i.c. coherentist – premises of a bioethical approach like principlism, it becomes apparent that this approach is equipped to deal with these challenges, not despite but rather because bioethics is a continuous work in progress. That is, to the extent that these technologies necessitate revisions to ethical principles like respect for autonomy, this illustrates the characteristic, open-ended and continuous task to interpret, specify and balance concepts and principles in the concrete context of changing medical practices. In that sense, the current wave of technological developments may require conceptual solutions and provoke a dissatisfaction with predominantly applied ethics, evoking a mirror image of bioethics' original emergence.

Applying a Bourdieusian perspective to the development of biobanks
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In social sciences, the emergence of population biobanks in the late 1990s was dominated by the Foucault- inspired discussion of (bio)medicalisation, characterised by concepts like "geneticization" and "genetic determinism" which express concern over the increasing geneticization of social problems that can lead to the naturalisation of (genetically caused)

inequality, in the larger context of dominating neo-liberal understanding that health is the moral obligation of each individual (and less the responsibility of state/society).
Alternatively, this paper takes a Bourdieusian perspective and argues that the discourse of genetic causation associated with the advance of genetic science should not be viewed in such a totalising way but rather as a feature of strategic public communication used by the researchers to gain symbolic capital in the context of the growing dependence of the scientific field on economic and political fields. Within genetics, the trend since the late 20th century has been towards growing acknowledgement of the complexity of genes and the multifaceted relations between genes and environment. However, in public discourse this often is presented using the language of genetic causation, "genetically determined traits" – choosing the topic and way of presenting which is bound to achieve attention in today's attention-deficit media landscape. Similarly, it is characteristic to publicise the results of new genetic discoveries with great pomp, while understating the uncertainties and overstating the potential, i.e. creating hype, with often needing to withdraw the most alluring promises in later stages. This is often in contrast with the uncertainty of results expressed in the academic publications. Biobanks as scientific ventures are especially dependent on external factors: their creation and upkeep require considerable financial input; the recruitment of a large group of sample donors requires significant popular support. It can be argued that the extent of hype in the public communication of each biobank is dependent on the specific socio-economy set-up of the biobank (i.e. the extent of its autonomy from the external fields) and its position in the national as well as the global knowledge-production field.
Empirically, the paper analyses the public communication of one of the earliest biobank ventures, the Estonian biobank project through the different phases of the project, from its initiation in early 2000s as a public-private joint venture, through its crisis years and its subsequent transformation into a publicly funded research institution. The analysis shows a shift from the prevalence of rhetoric of hope characteristic to the biotech industry in the early stages of the project to the growing prominence of genetic determinism in the communication of its results after the Estonian Biobank had established itself as a "normal" public scientific institution, with a relapse to the hype-mode in the promotion of a new capital-intense venture: personalised medicine.

How have biomedical ethics changed in the COVID-19 era?
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The COVID-19 outbreak resulted in significant changes in the practice of medicine. Telemedicine achieved prominence, patients were often subjected to triages because of ventilator, medication and eventually vaccine demands which surpassed availabilities, and social medical displayed an uncommon effect on the opinions of society and the willingness of patients to accept certain forms of therapy.
On the basis of periodic reviews of the ethical aspects associated with COVID-19 in the era, 2020-2022, the author presents three aspects by which COVID-19 appears to be changing the field of biomedical ethics. First, patient autonomy is increasing based on social media, on assumptions that do not necessarily show accepted scientific validity or the acceptance of professional societies. Second, the limited availability of therapeutics has augmented attempts to use scientific methodology to allocate the qualification for and distribution of therapeutic materiel. Third, the very presence of the outbreak has caused many to question the limited budgeting of public health facilities and governments for the prevention of future outbreaks.

Autonomy is a basis of medical decision making and one of the key features of biomedical clinic ethics. Historically it is balanced by the expert opinions and sometimes paternalistic attitudes of providers to do what is best for patients. The COVID-19 outbreak resulted in the about-face of many clinical and public health decisions, such as the advisability of masking. The changes in policies resulted in confusion for many and contributed to a reluctance to accept the views of public health authorities and perhaps consequently an increased autonomous demand for unproven therapies.
Such decisions were supplemented by the increasing power of social media and the difficulty for many patients to know whom to believe. For example, disproven medications such as hydroxychloroquine or ivermectin were often accepted by local authorities and accepted even by a few peer-reviewed studies. Meta-analyses exposed the fallacies in such studies but the community-at-large often failed to appreciate the basis of these analyses and how they support the recommendations of official subspecialty organization whose policies became the basis for senior medical advisors.
The fact that the outbreak occurred at a time when funding for pandemic prevention was diminished and during an era when certain government leaders questioned the validity of international health agencies, bewildered many citizens and attempts to prevent future pandemics ran the gamut from blatant racial antagonism to acceptance of the need for increased public health support for public health agencies and funding biomedical research that will lead to reducing the risk of future outbreaks.
The conclusion of the above is that COVID is making patients more insistent on demanding therapies, that COVID being the first outbreak of the social media is exposing the flaws of this relationship, and that COVID is making evident the need to increasingly support pandemic preparedness.

Cardiac Organoids: moral implications of their heartbeats

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Recent developments have cardiac organoids looking and behaving more and more like a beating heart. With these advancements, cardiac organoids (or: “cardioids”) will become increasingly valuable to science as a model for the human heart. However, these scientific advancements also raise a new ethical question: whether cardiac organoids are a new subtype of organoids warranting specific moral protections. Such specific protections have already been associated with other subtypes of organoids, mainly brain and embryo organoids. Moreover, this question has become particularly relevant since cardioids contract like a heart and the heartbeat has previously been used as a morally relevant feature.
The purpose of this paper is to examine the moral implications of the heartbeat in cardiac organoids by analogy reasoning. First, we will analyse the role of the heartbeat as a morally relevant feature in previous ethical debates on organ procurement and abortion. This role can be summarized as the heartbeat marking the morally relevant distinction between life and death. Then, we will evaluate whether the moral relevance of the heartbeat in these other debates translates to the heartbeat in cardiac organoids.
We conclude that, despite the normative role of the heartbeat in other ethical debates, the heartbeat in cardiac organoids is of no consequence for what is and is not allowed in the context of cardiac organoids. Unless a different feature of cardiac organoids is revealed to be morally relevant, cardiac organoids do not deserve to be awarded specific protections.

Womb Politics

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"Be fertile" has remained a powerful commandment in cultures based on the three monotheist religions and continues to dictate women's lives until today. Indeed, the unique organ with which women are born—or endowed—is not private. Drawing from my new book, I show in this talk that the womb has been and remains a public organ, politically ruled.

Figuring out values and wishes for (in)consistent advance directives – A qualitative study of concepts of life, dying and death using reflexive thematic analysis to disclose ethical implications

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In Germany, advance directives are legally protected as an expression of the author's self-determined will regarding his/her medical treatment in later life. So far, ethical debates primarily addressed their formal structure and legal validity whereas questions regarding their contents, such as personal motives and (often implicit) ideals of life and death, were scarcely considered. The ethical questions involved here require a broader examination of individual conceptions of a good life, e.g., which individual values and wishes matter when planning future healthcare? This requires a qualitative approach that allows a closer look at underlying concepts and values regarding life, dying and death in order to find out to what extent these concepts and values are well-considered and also consistent with the will expressed in the advance directive. To gain empirical knowledge about the abovementioned issues, qualitative interviews about life plans, experiences and ideas regarding health, illness, aging, dying and death, were conducted with 18 individuals in four age groups. These individual perspectives were analysed from the perspective of an ethics of the good life and contextualised with statements on the individual engagement in advance directives, e.g., on whether and how an advance directive has been completed. Reflexive thematic analysis was used to identify the underlying concepts of life, dying and death that influence the individuals' views on later life. Ways of living and dying are as varied as life itself. Along with that, they are addressed, experienced, suppressed and presented in a variety of ways. However, people are often not aware of their most fundamental values and convictions and their practical implications for advance care planning. Unlike qualitative content analysis, reflexive thematic analysis allows, simultaneously and equivalently, to examine manifest as well as latent content in order to identify guiding themes and concepts. Thus, this is an appropriate method to identify hidden aspects and implications that have considerable teleological weight, especially regarding personal orientations and individual impetus with regard to future life phases. Some interviewees express values and wishes regarding future phases and end of life, but no explicit plans. This indicates that self-determination does not automatically lead to the capacity to phrase congruent plans in line with an advance directive. This drawback has a high relevancy in light of the teleological ethics of the good life, as personal orientations for future life phases touch upon questions of people's awareness of what they are striving for: what they want and what they should want.
The consideration of individual values and wishes that motivate engagement in advance directives is highly relevant for medical ethics and health policy since they might have far-reaching consequences for individual healthcare, and also contribute to the bioethical discourse about the impact and constraints of advance directives. This points to the necessity of

appropriate methods to approach biomedical issues such as underlying concepts of a good life in the expression of patients' wills.

Objectivism, Subjectivism, and Values: Rethinking Health and Disease

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Philosophers of medicine have long divided theories of health and disease into two schools: naturalism and normativism. Naturalists claim that health and disease are determined solely by reference to objective facts about natural biological states; this objectivism (often referred to as realism) entails value-freedom. Normativists, on the other hand, claim that objective facts are insufficient and that health and disease are essentially value-laden; they tend to hold that the value dimension of health entails subjectivism.

Recently, Alex Broadbent[1] has offered a helpful new approach to the controversy. He shows that the naturalism/normativism dichotomy fails to recognize that each position conflates two different kinds of questions about health: (1) whether health is objective or subjective; (2) whether health is value-free or value-laden. Broadbent shows that there is no necessary logical connection between objective and value-free nor between subjective and value-laden. Forming the possible combinations of the two opposing stances regarding the two questions of realism and value yields a 2x2 matrix of four different positions: Value-Independent Realism (traditional Naturalism); Value-Dependent Realism; Value-Independent Anti-Realism; and Value-Dependent Anti-Realism (traditional Normativism). His terminology comes from William Stempsey's "Value-Dependent Realism" [2] which holds that health and disease are value-laden, but still objective (or real); this is possible if one takes at least some values to be objective. Broadbent advocates the remaining unexplored possibility of Value-Independent Anti-Realism. He takes health to be a "secondary property," extending John Locke's notion of "secondary qualities"[3] beyond observations dependent on sensory perception (e.g., color) to "secondary properties," which may include non-perceptual properties such as causation. For Broadbent, health is a "dispositional property of the natural functioning of organisms…to produce a certain cognitive response in us… express[ed] in health judgments" (p. 119). Broadbent gives this as one substantive position to support Value-Independent Anti-Realism, although he says there may be others.

This presentation offers an alternative inspired by the secondary property approach, but one that might be able to satisfy Value-Dependent Realism, Value-Independent Anti-Realism, Traditional Naturalism and Traditional Normativism: health as an emergent property. This could allow recognition of values that may be covert, but still are inherent in the judgments being made about facts; and (2) acknowledge the objectivity of these values. Emergence allows a deeper understanding of complex systems such as living beings. Different theories of emergence can be more or less accommodating to the four positions on the relations of objectivity, subjectivity and values.

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Beware of a two-tier transparency in clinical research

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Clinical trials can be more or less transparent in four areas: A) Study registration, B) Publication of results (as summary results and/or as journal publication), C) Sharing of data and codes, D) Study-related documents. Over the past 5 years, the EU Clinical Trials Regulation (CTR) 536/2014 and its predecessor laws had a demonstrably positive impact on i) study registration and ii) summary results reporting of drug trials. As the positive trend, however, can currently only be seen for these two specific elements of transparency and, moreover, only in the subgroup of drug trials, a "two-tier transparency" seems to be developing that differentiates between more strictly regulated (drug) trials and the less strictly regulated other trials. The presentation will substantiate the concept of a two-tier transparency with empirical data from recent meta-research studies in Germany [1-3]. Because of this recent development, academic institutions, funders, and ethics committees should be concerned with better implementation of all four transparency domains and should do so for all clinical trials. Monitoring the implementation of transparency in clinical trials across individual academic institutions, pharmaceutical companies, and national funders, would be an important first step to specify the need for action. As an example, the presentation introduce a newly developed dashboard showing indicators for clinical trial transparency across all 35 German university medical clinics [4].

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How well are ethical recommendations implemented in clinical research? Meta-research on clinical trial documents

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Research ethics, especially in the field of clinical research, is strongly regulated, partly by law and partly by established national and international guidelines such as the Declaration of Helsinki, requirement of research funders or journal submission requirement. These laws and guidelines cover ethical recommendations such as informed consent, favourable risk-benefit ratios, prospective registration of studies, unbiased and timely results reporting and more. For good reasons a lot of bioethics research deal with the important further development and specification of these ethical recommendations. But relatively few studies investigate the implementation of these recommendations 1. Are they implemented at all? And if they are implemented does this happen in a conceptually valid, effective and efficient way? Clinical trial documents including registered study protocols, investigator brochures, informed consent material, or results papers are not the only but an important way to investigate the

implementation of ethical recommendations. The presentation outlines examples for implementation studies that build on i) consent documents 2, ii) investigator brochures 3, iii) study registrations 4, and iv) results publications 5. The primary goal of this presentation is to illustrate the design of implementation research in bioethics, what conceptual and technical challenges might arise and how these can be addressed.

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Trust in science: a philosophical guide for making sense of empirical studies

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Trust shapes all aspects of human life. Thus, it is no wonder that different disciplines, ranging from sociology, psychology, organisation studies, STS, science communication and political science to philosophy, are intent on studying it. Sociologists are eager to measure the level of trust in different societies. Surveys show that public trust in scientists is relatively stable and higher than in most other institutions while in the public discourse we encounter an increasing vocalisation of distrust in science and science-based recommendations (e.g. in the recent vaccination controversies) in the increasingly polarised society, which has prompted institutional pressure on the science producing organisations to pay more attention to strengthening trust in science.

The concept of trust is complicated and, therefore, before measuring trust in science or scientists, we must define what we mean when speaking about trust or distrust in science. A difference should be made between trust in science as a social institution, in concrete scientists or their statements (epistemic trust), in the products of scientific activity (e.g., vaccines) or in those who manufacture these products (e.g., pharmaceutical companies) or propagate them (e.g., government institutions). When asking whether people trust science, we can consider science as an area of human activities or concrete disciplines or trends of science. The inquirer may also be interested whether scientists are considered trustworthy. At that, a difference should be made between trust in scientists' conduct and their statements (epistemic trust). Science, however, can also be understood as research results or products of science, e.g., vaccines or technologies.

Although many research disciplines deal with trust, philosophers should definitely be involved in the studies of trust, as they deal with concept analysis. The task of philosophy is to create conceptual clarity and correctly pose questions; then empirical sciences can search for answers.

The aim of this paper is to draw on the philosophical literature on trust and create a comprehensive map (scheme) of the different objects of trust (trustees) and mechanisms of trust that are at play in the different phases of scientific process; on what the trustworthiness of science is based. Such map can be used to as a guide for a meta-analysis of the wealth of empirical studies in trust in science (to specify which aspects of trust are in focus in the different studies) and allow us for a more comprehensive understanding of the state of trust of science in the fast -changing society.

Phenomenological Bioethics: Applicative Methodology, Critical Theory or Philosophical Anthropology?

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Phenomenology has been brought to the domain of bioethics in several, and mostly indirect, ways. Phenomenology has entered bioethics via the philosophy of medicine and medical humanities in studies of themes such as embodiment, pain, and illness, or via parts of bioethics that go under names such as caring ethics, feminist ethics, and narrative ethics. In this presentation I show how bioethics informed by phenomenology can be thought about and conceptualized in at least three distinctive ways. As a method in applying bioethical principles to ethical dilemmas, as a critical perspective challenging the dominance of autonomy based and utilitarian bioethics, or as a way of making the philosophical anthropology indirectly present in bioethics thicker as concerns embodiment and intersubjectivity.

Phenomenology can be used either to inform the application of principles – doing good, avoiding harm, respecting autonomy, and being just – by way of describing the lived experiences of moral dilemmas, or to criticize the contemporary set-up of bioethics and offer alternative approaches. The critical alternatives may be more or less radical in nature as concerns the way bioethics should be done – offering alternative principles or abandoning the systematic set-up of application altogether. It is typical of moral philosophers in the phenomenological tradition that they offer meta-ethical approaches rather than normative theories in their own right. Ethics in the phenomenological tradition has not been pursued as a development of rules to guide human actions but as a spelling out of the meaning of the good and the just in the first place.

The discussion about what type of perspective phenomenology is able to offer opens up a third alternative regarding the characterization of phenomenological bioethics in addition to the two approaches just mentioned. The field may be viewed as an opportunity to scrutinize and thicken the philosophical anthropology implicitly present in contemporary bioethics by addressing topics such as embodiment, being-in-the-world, self-understanding, vulnerability, suffering, empathy, responsibility, justice, and solidarity. This is the way of doing phenomenological bioethics which I view as the most promising one in the contemporary scenario, providing phenomenology in bioethics with a critical perspective absent in the first alternative, but still staying in touch with the tradition of bioethics as it is currently performed rather than becoming independent political theory.

The third version of phenomenological bioethics will make use of the first – providing adequate and rich descriptions of the situations to investigate – and it will end up related to the second, critical version when the standard prima facie principles of bioethics are transformed into richer normative concepts: human suffering versus flourishing, the possibilities of empathy and the risks of reification and instrumentalization, and the imperatives of responsibility and solidaric sharing, to mention the most important ones in the alternative I am defending (Svenaeus 2018).

Reverence
Svenaeus, Fredrik (2017) Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive. London: Routledge.

Health and Disease: Between Naturalism and Normativism

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Traditionally, the philosophical debate about health and disease is characterized as containing two opposite camps of theories: naturalism and normativism. Whereas naturalism is associated with terms such as 'value-freedom', 'objectivity', 'natural kinds' and 'science', normativism is associated with terms such as 'value-ladenness', 'subjectivity', 'social construction', and 'politics'. This dichotomous division into naturalistic and normative theories is unfortunate since it restricts the debate about health and disease to an unnecessarily limited space of possible positions, rather than stimulating progress. Recent novel contributions to the debate show that theories of health and disease need not be purely naturalistic or normative, but may be located somewhere in between.
The first purpose of this talk is to further advance this line of nuancing. I will do so in two regards. First, I will argue that we should pay extra attention towards a certain aspect of value-involvement. This aspect concerns whether a theory refers to values in its account of health and disease, or whether it is merely influenced by values. Second, I will argue that there are, so far unacknowledged, aspects that are important to consider when theorizing about health and disease. These aspects concern two different senses in which health facts can be taken to be objective. I will argue that a theory of health and disease may account for health facts as objective in one sense and simultaneously non-objective in the other sense.
The second purpose of the article is to argue in favor of a specific position, which the added nuances reveal. I call this position 'subjectively salient naturalism'. Subjectively salient naturalism is similar to naturalism, but differs in two important respects. First, it does not claim that a successful theory of health and disease needs to be value-free at the level where its operationalizations are justified. Second, it does not claim that health facts are about natural kinds in any ontologically strong sense. I will argue that if one is interested in scientific concepts of health and disease, subjectively salient naturalism is a more plausible position than naturalism.

Parental experiences of living with a child with a neurodevelopmental disorder and parents' perspectives on stem cell research: A semi-structured interview study

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Monogenetic neurodevelopmental disorders (mNDDs) comprise a selection of developmental disorders that are caused by single gene mutations and result in both neuropsychiatric and

somatic symptoms. Although increasingly (rare) genetic mutations are identified in patients with NDDs, disease-modifying treatments are not yet available and little is known about the pathophysiology of these syndromes. However, new stem cell technologies lead to the possibility to generate patient-own stem cell-based neuronal cell models to model the brains of patients with mNDDs in vitro, and to discover underlying disease mechanisms and innovative approaches towards personalized treatments. The development of these new approaches poses ethical questions, for example on the preconditions for including (vulnerable) children with mNDDs in biomedical research and the ethical acceptability of using neuronal cell models for research purposes. Stakeholder engagement is an important element in the ethics of new innovative technologies, and it is often embedded in research projects by conducting empirical research. To determine the preconditions under which the use of this technology is ethically acceptable and to gain a better insight into the needs and concerns of the patient community in clinical research and treatment development, we consulted parents of patients with mNDDs. We conducted a semi-structured interview study among parents of children with Kleefstra Syndrome and STXBP1 mutations living in the Netherlands (N=24). Interviews were thematically analyzed.

Our interview study showed the big practical and emotional impact of childrens' disorder and associated care on daily life as descripted by their parents. An important finding of our study is the impact of especially the psychiatric and neurocognitive symptoms of the children on the child itself and on the family as a whole. In our presentation we will discuss the moral perspectives of parents on stem cell-based neuronal cell models and treatment development, and their considerations in deciding whether they let their child participate in both observational and clinical research. Another finding is that although the interviews were conducted to investigate parents' (moral) perspectives on new approaches to develop personalized treatments for their children, we discovered that parents' needs are mainly in the social domain focusing on social support for children with special needs and sufficient accessibility of care. Finally, we want to highlight the ethical and practical significance of community involvement and empirical research in research projects using new innovative health technologies, for instance to develop sufficient practical ethical guidance, to gain input for the normative analysis of these technologies and to ensure that research aims sufficiently align with the values and perspectives of those who will be affected.

Health data sovereignty: A normative analysis

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The concept of data sovereignty is becoming increasingly common in the European Union policy discourse. The health domain could benefit from this approach, because issues of privacy and responsible use are central. Health data sovereignty refers to the idea that a patient as a data subject is in control of her data. However, tensions emerge if the future potentials of machine learning and big data derived from electronic health records, sensor technology and self-tracking applications will be unleashed. The aim of this paper is to provide a conceptual analysis of health data sovereignty and to discuss the ethical implications of such a concept.
We proceed in three steps. First, we gather and analyse different definitions of health data sovereignty in governmental and policy documents (international, regional and national level). This empirical step allows us to map the diversity of different concepts and the context of their application. Thereby, we identify the spectrum of possible justifications for donating or withholding health data.

Second, to provide a theoretical background of health data sovereignty, we examine insights of the data justice and data security discourses in academic literature. This allows us to highlight similarities and differences between health data sovereignty and other concepts in use.
Third, we discuss the ethical implications for maintaining or ceding health data sovereignty within the healthcare system. Particularly, whether we should share health data altruistically, conditionally to access health services, or to do our part to promote the common good.

Conscientious Objection as Obstetric Violence

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Much has been written on the impacts and ethics of conscientious objection to reproductive healthcare services such as abortion and emergency contraception. While some see a balance to be struck between protecting conscience rights and upholding access to reproductive healthcare, other scholars have labelled conscientious objection as 'dishonourable disobedience' (Fiala and Arthur 2017) and even as 'an act of heresy' (Montgomery 2015). In my paper, I seek to contribute a new perspective to this debate by framing conscientious objection to abortion as a form of obstetric violence. The term 'obstetric violence' has developed within feminist literature as a concept to name the dehumanising, abusive, and coercive treatment by healthcare professionals of women in pregnancy and birth contexts. Importantly, obstetric violence is recognised as a gendered and structural issue, rather than as instances of individual mistreatment. Scholars have begun to expand this concept to other areas of reproductive healthcare, including abortion. Acts such as refusals of care and gaslighting have been recognised as obstetric violence within the pregnancy and birth context, with emphasis on how these acts are informed by and reinforce harmful gendered stereotypes around pregnancy, motherhood, and women's reproductive roles. Moral objections to abortion, prioritising the life and wellbeing of the foetus over that of the pregnant woman, also perpetuate these stereotypes.
In this paper, I present three key arguments in favour of recognising conscientious objection as obstetric violence. Firstly, widespread conscientious objection can obstruct access to abortion, causing harms ranging from socio-economic disadvantage for those having to travel elsewhere, the forced continuation of pregnancy, and even death where objections are made to life-saving abortions. I characterise these harms as a structural and gendered violence caused by the refusal to provide care. Secondly, some healthcare professionals engage in 'extreme objection' where they not only refuse to provide abortion services but go out of their way to obstruct patients from going on to access services. This form of obstruction mirrors the gaslighting and coercion identified as obstetric violence in other contexts.
Finally, while some patients may go on to access an abortion with minimal delay following a conscientious objection, I argue that the objection is nonetheless harmful. By perpetuating gendered stereotypes around reproduction and stigmatising abortion seekers, conscientious objection represents a dignitary harm against women which amounts to obstetric violence. By framing conscientious objection as obstetric violence, I do not argue that individual objections should be treated as violent. Rather, this framing enables conscientious objection to be viewed as a significant harm to be addressed at a structural level. Instead of leading to legal or policy regulations, I conclude that this framing highlights the urgency of combatting anti-abortion attitudes and gendered stereotypes at a socio-cultural level.

Humanity as Meaning in Face of Dying Other: The challenges of dignified care in Lithuania

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The paper aims to reflect the idea that humanity of a human might be revealed best in responsible relationship with the dying Other in terms of the French philosopher Emmanuel Levinas. Following E. Levinas - a human asking for help uncovers his face in nudity, without any mask. The face of suffering Other is asking not to be left alone. In the face of suffering Other, one cannot refuse, one is obliged to respond and to take responsibility for the care. The relationship between the caregiver and the person under care is asymmetric and heteronomous. While trying to find out explanations why does someone choose to take moral responsibility for the care of the other despite high risk of losing personal life, becoming a voluntary hostage during the process of care, and facing physical, psychological, financial burdens, and continue living with this death of the Other, a qualitative and a quantitative study were conducted in Lithuania in 2020. The results showed that caregivers who took responsibility to care for their dying spouses / children / parents / friends did this involuntary – they were not able to refuse, because of this moral responsibility to respond to the enquiry of the suffering Other. It seems that the act of taking responsibility is not a rational choice, but a vocation – I am not choosing, I am obliged to respond and take responsibility. This responsibility is not transferrable, no one can replace me, and I am not able refuse. Precisely this situation reveals uniqueness of myself as a subject. To bear the suffering and death of the Other is the highest form of subjectivity. And this is inextricable identity of the subject. This moral obligation is not about the dying person, it is about the humanity of the person who responds (or not) to the dying Other. The studies revealed that close relationships with the patient, patient's request, and previous nursing experience were the main motives for becoming a caregiver. After taking multiple responsibilities, the caregiving process resulted in physical issues, loss or reduced employment possibilities, lost or reduced communication possibilities with others, and psychological or emotional exhaustion. The phenomenon of taking responsibility for the dying Other even with a risk to face negative consequences to the personal life as interpreted from the Levinasian perspective revealed the relational nature lying in the caregiving process as the major way of assuring dignity of a person dying from severe illness: dignity lies within relation with oneself and the world.

Non-empirical Methods for Ethics Research on Digital Medicine, Healthcare, and Public Health: A Systematic Journal Review

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Since the „birth of the empirical turn in bioethics" (Borry) empirical methods from the social sciences have steadily gained ground in bioethical research. This trend also includes recent attempts to apply computational methods to bioethical research questions in the digital era. However, empirical methods alone cannot establish the normative validity of moral statements. Therefore, non-empirical argumentative and conceptual philosophical methods are still needed, e.g., to bridge the "is-ought" gap. If it is true that new bioethically relevant phenomena require new research methods, the question arises whether ethics research on digitalization in medicine, healthcare, and public health does also fostering new non-empirical methods.

While empirical methods in bioethics are well researched, there is a research gap regarding non-empirical methods. We suspect that this is due to a lack of awareness of the diversity of non-empirical methods as well as an often implicit choice of methods that is not documented in detail in the research process. In this study, we want to have a closer look at the reporting of non-empirical methods in argument-based research articles. We differ from previous research in focusing not only on (systematic) reviews but primarily on articles reporting non-empirical research in original contributions.
We have chosen the topic of ethical issues of digitalization in medicine, healthcare and public health because, as digital technologies become more widespread, new fields of ethics research are emerging (e.g. AI ethics, digital ethics, data ethics) where the use of new methods is to be hypothesised. We want to know whether there are any methods that are particularly suitable for researching ethical issues arising from digitalization. We will present the results of a journal review in which we identified non-empirical methods used in articles that have been published in high impact bioethical journals in the last four years.

How to do normative interviews in empirical ethics: A practical methodology
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The literature on practical methodologies of interview studies in empirical ethics is surprisingly sparse. In this paper, I provide such a practical methodology. The methodological, metaethical and metamethodological, description and discussion will cover the main steps of the study process – and their interconnection – all the way from the initial research idea stage to the article writing stage. A central topic is how and why interview studies in empirical ethics differ from standard varieties of qualitative research methodologies in the social sciences, both in purpose and practice. I illustrate the methodology with my own experiences with normative interview studies, and with studies from the literature.

The role of trust in consent and health care research on addiction
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Substance use and its problematic varieties are studied extensively in different fields. These studies often involve participants who use the substances, especially if the field is related to health care and medicine. Over the decades, bioethics and research ethics have identified ethical challenges in research and treatment. In the context of treatment, trust is typically identified as a central theme and its lack is seen to generate various problems. This seems to apply regardless of who it is who does not trust whom. For instance, individuals with substance use problems may often regard authorities and institutions with suspicion, especially if the substance they use is illicit and there is stigma, while the professionals may occasionally doubt the honesty of the individuals' reports of substance use and commitment to the care.
However, issues of trust seem different in the context of research. Lack of trust by the potential study participant most likely results in not consenting to the research. Consequently, the participants can already be seen to hold at least a minimum amount of trust for the research. It is also easy to imagine that building trust would be important from the researcher perspective too. Surprisingly, the Declaration of Helsinki does not mention 'trust' in its ethical guidelines for the medical researchers even if research ethical guidelines in research with human participants trust is identified as fundamental (e.g., TENK 2019). Furthermore, it is noteworthy

that trust can be seen as a contributor for a common challenge in medical research, namely in therapeutic optimism that is a form of therapeutic misconception. Is there too much or "wrong kind" of trust in therapeutic optimism?
There is discussion whether people with substance use disorder are particularly vulnerable for therapeutic misconception in randomized controlled trials for treatment of substance use disorder. Therapeutic misconception refers to situations where research participants mistake the research as primarily treating patients rather than testing interventions. Previous research on individuals with substance use disorder indicates lower research literacy with higher susceptibility to misinterpreting study information, misunderstanding what research is and how it is carried out, increased willingness to take risks in research and having external influences on enrolling in the research. In this kind of circumstances, issues of trust seem to be present even if they are not explicitly discussed. Willingness take risks, for instance, seems to require an amount of trust for potential gain in order to happen.
In the presentation, I will first spell out the kind of dynamics that trust seems to play in addiction-related health care research and consider in more detail therapeutic optimism, e.g., unrealistic expectations for the medication or treatment, as a form of therapeutic misconception. In the presentation, I will ask whether the research on the perceptions of individuals with substance use disorder of their expectations for the intervention (such as new medication) should also be considered as a form of misplaced or unjustified trust.

The data relationship: A citizen conception of health data
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As part of the European Joint Action Towards a European Health Data Space (TEHDAS), the Healthy Data e-consultation was organized to engage citizens on the ethical, legal and societal implications (ELSI) of the creation of a European Health Data Space (EHDS). The key question relayed to citizens was about the acceptability of secondary use of health data. Through an extensive communication campaign, citizens from all over Europe were confronted with several informative materials (a quiz, a story, a case, …), designed to incite deliberation on the ELSI of secondary use of health data and inspire citizens to share their views on the platform. The consultation was organized by Sciensano (Belgium), Health Data Hub (France) and NHS Confederation (UK) between December 2020 and May 2021. In total, 5932 contributions were gathered, thematically analysed and transformed into recommendations for the EHDS.
Citizens referred to data or types of data in many different ways. For example: my data, our data, sensitive data, valuable data, data about X or Y, data for X or Y, datasets, linked data, anonymized data, data rights, data preferences. However, in all these contexts, there was one core sentiment that was universal to all citizen contributions: "our health data belongs to us". The rationale behind these statements ('my data', 'it is our data' etc.) seems to be embedded in the recurrent conception of data by citizens as a piece of their identity, of their history, of their lives. They feel that they are related to it. Hence, sharing, using, and governing their health data is to enter into a data relationship with the citizen.
From the qualitative analysis, several elements of the data relationship were identified: risk (privacy, data security), purpose, anonymization, safeguards (access, technical safeguards, citizen control), transparency, communication, information, literacy, engagement, ... The data relationship is a balancing act: when one element changes, it can affect all other elements. For example, for a highly supported purpose, citizens have higher risk tolerance.
To build a trusted EHDS, decision makers must be aware of the needs and values of citizens. Data users should recognize that they are one cog in a bigger system, and that every change

they make needs to be balanced with the other elements of the data relationship. Likewise, citizens are an important cog in this system and their views and values must be incorporated into any resulting framework. Thinking of data use as a data relationship can be a first step towards respecting data subjects.
Continuous citizen engagement can be a method to work on this relationship. It can prevent shadowboxing, making sure that concepts like privacy, data ownership, common good, commercial use, etc. align between citizens, data users and the governance framework.

Ethicists Facing scandal: What to do when methodology is lacking?
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Health care ethics is young relative to other medical or medical adjacent disciplines. This relative newness means that healthcare ethicists and those who employ them are likely to face unprecedented situations for which there is no established methodology. This presentation will explore the lack of research and established methodology for working through a medical scandal. A contemporary example which was recently and prolifically reported upon in the news in the United States will frame this discussion. The situation involved an Ohio physician who was charged with killing 25 patients. While the physician was ultimately found not guilty of criminal charges, the situation took an unprecedented toll on all involved. The experience of the embedded ethicist who was asked to assist the healthcare system in working through this complex situation involving physicians, nurses, medical residents, and pharmacy professionals among others will provide the backdrop.
This presentation will argue that there are currently insufficient methodological frameworks from which ethicists can operate when such scandalous and emotionally laden situations occur and will argue that the lack of method poses significant professional risks, including loss of professional reputation, possible legal liability, and other harms for the health care ethicists whose professional expertise is sought to assist in working through these difficult situations. Additionally, scholarly research, which can often be used to discern best practices and offer guidance, appears to be lacking in professional literature on this topic.
While history is replete with examples of physician or medical wrongdoing, many of the situations occurred prior to the firm establishment of healthcare ethicists being embedded in medical systems. Historic examples led to structured review and the establishment of proactive frameworks to mitigate harm moving forward. For example, in medicine, in the case of medical error, there is an established though perhaps rudimentary methodology for working through a medical error and apology based in states law, research on the impact of apology, and other commonly accepted principles and practices.
This presentation will use the real-world example described above to argue that current frameworks of clinical ethics are insufficient, by themselves, to guide the work in such situations as are frameworks around medical error and apology. Thus, a framework based on justice, fidelity, and veracity should be foundational in such situations. Finally, this session will call for transparency and collaboration amongst ethicists who have faced such problematic situations to share collective wisdom, develop a substantial framework for work in these crises to protect both the profession and the professional reputations of ethicists who face them. This work is vital to the growth of clinical ethics and the obligation of all practitioners to advance the profession and protect those who serve as health care ethicists.

A Phenomenological Approach to Vaccine Hesitancy: Embodiment and the Life-World

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There is a strong scientific and medical consensus that vaccination is one of the main ways to control infectious diseases, including COVID-19 (Dubé and MacDonald, 2018). However, there are many serious challenges to vaccination efforts, one of which is vaccine hesitancy, defined by the WHO (2015) as "delay in acceptance or refusal of vaccines despite the availability of vaccination services." Although vaccine hesitancy is not a new phenomenon, it is undeniable that there has been a steady growth in vaccine hesitancy over the past few decades (Dubé and MacDonald, 2018; WHO, 2015; IA2030, 2021). In 2019, the WHO listed vaccine hesitancy among the top ten threats to global health (WHO, 2019), and the COVID-19 pandemic has only made it more urgent to understand the factors and motives behind vaccine hesitancy. Although a plethora of studies have been carried out to understand vaccine hesitancy, in our research study, we use a philosophical framework to approach the issue. Specifically, we examine COVID-19 vaccine hesitancy in our country by conducting a phenomenologically informed qualitative research study based on the methodological framework called the "Phenomenological Interview" (Høffding and Martiny, 2016), which integrates the qualitative interview with the conceptual framework from phenomenological philosophy. In our phenomenologically informed research study, we use the phenomenological conceptual framework of embodiment to analyze the embodied experience of vaccine-hesitant individuals. One of the concepts that can be used to analyze and better understand the embodied aspects of vaccine hesitancy is Edmund Husserl's concept of the life-world. Although the concept of the life-world is an exploratory and provisional concept in Husserl's later philosophy, one of its principal characterizations is that it is the world of experience, the intuitive (perceptual), concrete, and taken-for-granted world of our embodied everyday practical activities and interactions with others. As such, it is the world that is the primary source of trust and certainty in our lives upon which we engage with the world. This world is contrasted with the world of science, the objective, ideal, and abstract world (Moran, 2012, p. 181). Based on our interview material, I will argue that one way to understand vaccine hesitancy is in terms of an incongruence or even a conflict between the life-world and the world of science. If one's life-world does not support or even contradicts the objective, ideal, and abstract world as it is presented by government, healthcare, mass media, or scientific representatives, one will be hardly convinced by the latter to vaccinate. It is only when a problem, contradiction, or uncertainty arises within one's life-world that one might turn to scientific knowledge.

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How meta-research may help in ethical analysis? The case of umbrella trials in oncology

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Novel precision oncology trial designs, such as umbrella trials, are designed to test new anticancer agents in more effective and affordable ways (1). However, they present some ethical concerns referred to scientific validity, risk-benefit balance and informed consent (2).
The aim of my presentation is to discuss these issues in umbrella trials, and to illustrate how meta-research may help in ethical analysis. I will present the results of both theoretical approach and meta-research (2, 3). For meta-research we searched Embase and PubMed for cancer umbrella trials testing targeted agents or a combination of targeted therapies with chemotherapy

(3). We included solid tumor studies published between 1 January 2006 and 7 October 2019. We measured the risk using drug-related grade 3 or higher adverse events (AEs), and the benefit by objective response rate (ORR), progression- free survival (PFS), and overall survival (OS). When possible, data were meta-analyzed. Of the 6207 records identified, we included 31 sub-trials or arms of nine umbrella trials (N = 1637). The pooled overall ORR was 17.7; the median PFS was 2.4 months, and the median OS was 7.1 months (benefit). The overall drug-related death rate was 0.8%, and the average drug-related grade 3/4 AE rate per person was 0.45 (risk). Our findings suggest that, on average, one in five cancer patients in umbrella trials responded to a given therapy, while one in 125 died due to drug toxicity. Our findings do not support the expectation of increased patient benefit in cancer umbrella trials and provide crucial information for the extended ethical analysis.

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Evidence-Based Medicine, the Electronic Medical Record, and Values in Medical Science

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What role do values play in the Electronic Medical Record (EMR) system? I argue that the EMR was created on the same base assumption that underlies the principles of Evidence-Based Medicine (EBM): utilizing basic logical reasoning to link evidence to clinical practice is the best way of doing medicine. Though there has been significant pushback to the treatment of evidence as authority in Evidence-Based Medicine, the role of the EMR has flown under the radar. I argue that we cannot remedy the issues underlying EBM until we identify how the EMR makes EBM possible. EBM is not practiced alongside the EMR but rather through it. The historical development of the modern-day EMR, which I trace through the early work of Dr. Lawrence Weed, showcases how it was built on positivist principles through which clinical decision-making is practiced today. At the core of this argument is a call for social values in (medical) science. Without acknowledging the unavoidable influence of social values in medical practice, including clinical decision-making for diagnosis and treatment, EBM leads to underdiagnosis and misdiagnosis. To mitigate this harm, we must first acknowledge how EBM is both reliant on and practiced through the inherently positivist structure of the Electronic Medical Record.

Medical Humanities: Embracing art, literature, and philosophy to enrich medicine

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Recent developments in technology have changed the practice of medicine on various levels. The employment of digital devices and artificial intelligence have modified not only the treatment of patients but also the relationship between physicians and patients.

All is geared toward faster, more accessible, and reliable health care. However, there is a growing need to push forward toward the implementation of another equally important field of knowledge in medicine: medical humanities.
Although the association between medicine and the arts seems like a new idea, it has been examined in Greek mythology with Apollo being held as the God of music, poetry, and healing. The field of medical humanities aims toward an interdisciplinary approach to medicine. It borrows insights from other fields of study such as art, history, philosophy, and literature. Medical schools have realized the importance of including medical humanities in their curriculums to encourage students to develop medical wisdom and thus take the time to pause, ask a question, read a poem or look at an artwork then simply, think!
I propose five scenarios of how the field of medical humanities could come to aid in medical practices.
In the first scenario, we could trace the history of an organ or a disease as it was depicted in arts and literature. An example, the thyroid gland: When enlarged, it is easily noticeable. This was depicted in ancient sculptures of various civilizations, Medieval and Renaissance paintings, even before the thyroid gland and its diseases were known in medicine. Shakespeare described the goiter in his play The Tempest as "a wallet of flesh" in mountaineers who probably had iodide deficient diet caused by living in the mountains.
The second scenario is to examine, from a socio-historical point of view, how people reacted to a given medical problem, such as epidemics and pandemics. This could lead to a better understanding of human behavior which probably remained the same throughout the centuries.
The third scenario is to Interact with global incidents/ news from a medical point of view such as the use of hormones by athletes, or the participation of athletes with the disorder of sexual development (DSD) in the Olympics.
The fourth scenario is to learn from the biographies of writers, artists, or composers, tracing how medical diagnoses were reflected in their creative works. Anxiety is often linked to the work of the painter E. Munch through his famous painting, The Scream, but can we evaluate the role of his broken childhood as a cause of his neurosis?
The fifth scenario is to potentially make a medical diagnosis: Did the composer S. Rachmaninoff who had very big hands and long fingers have Marfan syndrome or acromegaly as a diagnosis?
Examining these questions broadens our spectrum in observing the trajectory of diseases throughout history and through the lens of the arts. Medical humanities as a field embrace many disciplines and could complement and enrich the purely scientific and technical studies of medicine.

Failure culture and gender identity. A nationwide empirical study amongst rescue service staff.

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Causes of medical mistakes as well as dealing with mistakes in medical practice has rarely been researched. Limited data suggest inadequate communication as a leading cause for medical faults. In particular, that has been shown for emergency responses. There, communication errors contribute significantly to harm of patients.
We researched communication skills, attitudes with respect of communication during emergency responses as well as handling with failures amongst German rescue workers. We used a structured interview. Interviewees were enquired about their self-estimation of the frequency of errors during services, handling with failures and consequences for patients. In

this paper we report our analysis with respect of gender differences of dealing with medical errors.
714 rescue workers were interviewed. 68% of which reported about having harmed patients by own mistakes.
Part of results had been published elsewhere (Plos One 2021, 3: 16(5), doi: 10,1371) and are still in process of publishing. Here we report data informative with respect to gender identity.
Taking into account that most errors are caused by malfunction of communication within the emergency teams we analysed respondees self-reported causes of own mistakes and their handling and reaction afterwards.
Here we found significant differences with respect to behaviours and attitudes between sexes (female vs. male), e.g. such as striving to avoid impression of incompetence (female > male) or feeling ashamed after failures have occurred (female > male). Similar differences were seem concerning other items.
In summary, female rescue workers more frequently felt ashamed after failures had occurred and more often feared to be sanctioned afterwards. During training as well as continuing education of rescue team staff handling with mistakes has to be addressed more explicitly provided adequate attention is given to gender differences in dealing with errors happened.

Human Dignity in Home Hospice

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Background: Human dignity is considered a highly rated value in democratic countries and serves as the basis for central values such as autonomy and informed consent. Thus, the value of human dignity is the foundation for appropriate clinician-patient relationships.
The Israeli 2005 Dying Patient Act standardizes medical care of dying patients, balancing the value of the sanctity of life and the value of the patient's autonomy and quality of life. The law states that clinicians must, with certain restrictions, honor dying patients' wishes not to prolong their life artificially. In addition, the law states that clinicians must provide dying patients and their families with palliative care.
Thus, over the past decade, the Israeli healthcare system has been offering dying patients the choice of receiving end-of-life care not only in general hospitals but also in supportive care institutions, such as hospices, as well as at home (home hospices).
The ability to receive end-of-life care at home raises questions regarding the perception of human dignity for dying patients in a home hospice framework, as well as expressions of providing human dignity to patients from the point of view of a multi-professional team providing home hospice care. In order to examine these questions, we undertook a qualitative study with clinicians.
Research Methodology: Semi-structured interviews with 17 multi-professional team members working within the same home hospice framework, analyzed through narrative analysis.
Findings: The findings present a rich, complex picture of the challenges and implementation of the human dignity value in the home hospice as based on the Dying Patient Act. The challenges include dealing with a care framework which is also the patient's home, in which the clinicianis acting within an unknown field and needs to act with particular sensitivity, as different from hospital or clinic care; tension between patients' wishes and those of their families, for example in a situation when the patient wishes to die at home and the family does not feel it can take it; and dealing with patients' changing wishes, when they first wish to die at home and at a later stage ask to be taken to the hospital.

Conclusions and Recommendations: It is necessary to train clinician teams in end-of-life communication skills in order to allow for honest discourse regarding the patient's end-of-life wishes and promote the honoring of those wishes within the framework of the home hospice in the spirit of the Dying Patient Act.

Media content analyses in bioethics

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To assess the ethical and social implications of public health issues and new health technologies, the assessment of public debates – as portrayed in the media – is of crucial importance. Drawing from examples from my own and others' research, the aim of this contribution is two-fold: On the one hand, it sets out to present the different methods to empirically assess the content of mass media debates relevant to bioethics. It covers aspects of qualitative, case-based analyses; quantitative comparative analyses using predefined codebooks; and automated text analyses using Natural Language Processing. Moreover, theoretical frameworks from the media and communication sciences, such as Framing and Public Engagement with Science and Technology, will be discussed, including their relevance and usefulness for bioethics.
On the other hand, this contribution intends to discuss the challenges and opportunities of combining descriptive media content analyses with normative considerations. First, I will argue that media content analyses – if designed with that intention – can be useful for comparing media content (description of what is) with normative claims, principles, and theories (claims how it should be) to develop recommendations for science communicators, journalists, and policymakers. Second, acknowledging the is-ought problem, I will discuss to what extent normative considerations made in the media can be of use for bioethical inquiries. Third and finally, I will defend the usefulness of providing purely descriptive, well-performed media content analyses to set practical evidence useful for separate, more high-level normative reflections.

The right to die in dignity? Views and values of Israeli Health Care Professionals regarding lifesaving treatment for refusing patients

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The Dying Patient Act was enacted in Israel in 2005.It defines a dying patient as suffering from incurable medical condition, and their life expectancy does not exceed six months if treated. In practice, the law does not refer to patients not considered by it as dying patients given their life expectancy (for example ALS and Dementia patients). Given the legal situation on the one hand and the wishes of those patients to die in dignity on the other, several governmental guidelines and court rulings from the past few years open the door for passive euthanasia for such patients, using gradient decrease of resuscitation and oxygen saturation in certain conditions. At the same time, a recent court ruling regarding the provision of life saving treatment to a refusing patient emphasized the sanctity of life and its supremacy over other values including patients' autonomy. Given the unclear legal and regulatory situation, in order to capture health care team members' views and perceptions on the topic, we have conducted a pilot survey in April 2023 for which 40 psychiatric physicians and nurses responded. The results of which will be

presented and insights on the uncertain situation regarding the right to die in Israel will be discussed.

Surprising Pandemic Experiences: A Confrontation between Principle-based and Virtue Ethics and a Plea for Virtue Ethics Training for Medical Students and Residents. A rudimentary outline of a Four-Step Model

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In past years, physicians have, with a certain continuity, reported about increasing numbers of burnout, depression and compassion fatigue in their daily practice. These problems were attributed, not only but also, to a loss of public trust and an increase in violent behavior of patients and family members towards medical professionals in all walks of life. Recently, however, during the breakout of the COVID-19 pandemic since 2020 there were public expressions of appreciation and respect for health care workers that almost universally have been assessed as indications of a reestablishment of that public trust in physicians and appreciation for the medical professions' commitments. In other words: shared experiences of what society was in need of: the experience of a 'common good'. Those responses during the Covid-19 pandemic increased positive feelings among practicing physicians , such as commitment, solidarity, competency, and experiences concerning obligations for the common good and a sense of belonging to one and the same community for all.
Essentially these responses of raised self-awareness of commitment and solidarity between (potential) patients and medical personal point towards the social importance and power of these values and virtues . This shared domain in ethical sources of behavior seems to hold a promise of overcoming gaps between the different spheres of doctors and patients. That justifies stressing the relevance of this shared domain of Virtue Ethics in the training of physicians. In this article therefore we shall make a plea for the relevance of Virtue Ethics before proposing an outline of an educational program for Virtue Ethics Training for medical students and residents.
Let us start by very briefly presenting on Aristotelian Virtues and its relevance to modern medicine in general, and during the current pandemic in particular. We shall follow up this short presentation by a Virtue Ethics Training Model and the respective settings in which it takes place. This model has four steps: a. Include moral character literacy in the formal curriculum; b. provide ethics role modeling and informal training in moral character in the healthcare setting by senior staff; c. Create and apply regulatory guidelines regarding virtues and rules; and d. Assess success of training by evaluation of moral character of physicians. Applying the four-step model may contribute to strengthening the development of moral character in medical students and residents, and decrease the negative consequences of moral distress, burnout and compassion fatigue in HCP. In the future, this model should be empirically studied.

Human enhancement in bioethical discussions: a computational approach

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This paper uses topic modeling and citation data to systematically analyze scholarly discussions on ethical and regulatory issues stemming from the direct manipulation of the human genome and from other recent developments in genetic engineering.

Although the direct manipulation of the genome of organisms (e.g. plants for agriculture) was embraced by scientists years ago, and discussions on regulatory issues concerning genetic engineering have been vivid since the 1970th (e.g. the Asilomar Conference on DNA in 1975), the development of CRISPR/Cas9 method in 2012 is considered a revolution due to its efficiency and cost-effectiveness. In 2015, CRISPR/Cas9 germline modifications were first used in non-viable human embryos, opening a real possibility of making permanent, heritable changes to the human genome.

These technological developments are related to one of the most central challenges in ethics: shall we care only about the benefits and harms of particular identified people, or also about the welfare in the world that may involve creating 'better' people in the future? Some scholars claim, that ethical and regulatory issues stemming from genetic engineering are foundational for at least some parts of bioethics, e.g., the editor-in-chief of The American Journal of Bioethics (AJOB) stated in the 100th-anniversary issue of the journal: "Dolly the sheep gave birth to AJOB, that the journal issued from developing embryonic stem cells" (Magnus 2013).

A standard manner in which practitioners of an academic discipline reflect upon the development of their field is through "close reading" of selected texts mediated by their personal experience and academic interests. Here is a typical statement based on such an approach: "enhancement is coming to the forefront of bioethical scholarship" since this topic "combines cutting-edge science with mainstream philosophy" (Harris 2012).

The approach we adopt in this paper takes seriously the epistemological question of how one can justify this type of statements. Referring to our previous studies based on the corpus of about 20.000 texts published since 1971 in seven leading journals in the field of bioethics (Bystranowski, Dranseika, Żuradzki 2022a, b), we use a "distant reading" approach based on topic modeling and citation data. We concentrate on the topic we previously interpreted as Enhancement (characterized by terms "enhancement," "enhance," "technology," "intervention," "cognitive," "capacity," "trait," "morally," "improve," "bioenhancement"), which was "the biggest winner" in terms of relative growth in our corpus (the increase of the mean prominence from 0.03% in 1971-75 to 0.97% in 2016-20). We also analyse four correlated topics that are the most frequently present together in the same texts with Enhancement: Germline, Ecology, Offspring, and Genetics. We delineate a sub-corpus of papers that 'belong' to this five-topic cluster, which we interpret as the core of bioethical discussions on ethical or regulatory challenges stemming from genetic engineering.

This enables us to conduct several interesting analyses: Which ethical and regulatory challenges seem the most important for bioethics? How closely does the field follow recent scientific breakthroughs? To which philosophical problems, if any, bioethics refer while discussing genetic engineering and related topics. The result of our study may be interpreted as undermining the claim that bioethical discussions on these matters "combine cutting-edge science with mainstream philosophy".

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