ABSTRACTS

LIMEC

12-13 JUNE 2025

FORTE:
Forskningsrådet för hälsa, arbetsliv och välfärd

KEYNOTE SPEAKERS

The Ethics of Predictive Medicine: Dementia Risk Prediction between the Right to Know, Responsibilisation and Technologies of Hope

Prof. Dr. Silke Schicktanz, Institute of Medical Ethics and History of Medicine, University Medical Center Göttingen

In the domain of personalized medicine, prediction has emerged as a pivotal element. Optimists contend that prediction enables preemptive actions. It utilizes physiological or digital biomarkers to furnish statistical data regarding the onset or progression of a disease.

The field of Alzheimer's disease (AD) represents a particularly challenging area for such prediction. New blood biomarkers have been shown to predict higher risks for AD with a lead time of 10 to 15 years.

In this presentation, I will engage in a dialogue on the ethical considerations of predictive testing, being accompanied by empirical insights into public attitudes. I explore the implications of predictive testing on the liberal right to information, juxtaposing it with communitarian concerns of promoting hope and (self-)responsibilisation.

Precision Medicine and Distributive Justice - Wicked Problems for Priority-Setting and Democratic Deliberation

Prof. Leonard Fleck, Center for Bioethics and Social Justice, Department of Philosophy, Michigan State University

What is most distinctive of the ethical challenges raised by precision medicine is that they are "wicked" ethical problems. A "wicked" ethical problem is defined as one where every attempted resolution results in an equally ethically problematic outcome, or an even more problematic outcome. For example, hematologic cancers can be treated with CAR- T-cell therapies with a front-end cost of $475,000.

Roughly 30% of those patients will survive less than a year. Would it be ethically acceptable, as a matter of health care justice, to do research aimed at finding biomarkers that would identify such patients before the fact with 90% confidence so that we could deny them that therapy (presumably to re-allocate to higher priority health care needs)? There are dozens of problems like this generated by our current deployment of precision medicine.

I argue that none of our theories of justice have the resources to yield satisfactory responses to these ethical challenges.

We need to rely instead on fair and inclusive processes of rational democratic deliberation constrained by the relevant medical facts, a range of considered judgments of health care justice, a public or political conception of health care justice (building on Rawls), what I describe as constitutional principles of health care justice, and a certain understanding of wide reflective equilibrium.

The result will be deliberative judgments, autonomously generated, that are "roughly just" (given the wickedness of the problems). The ultimate goal is to prevent cancer and precision medicine from capturing an unfair share of health care resources.

PLENARY SESSION

What's the Use of Medical Ethics?

Chair: Lars Sandman

Silke Schicktanz, Leonard Fleck, Marit Karlsson, Martin Henriksson

A self-critical question the field of medical ethics, in being an applied ethics, should ask itself is: "What's the use of medical ethics within the clinic and at the policy level? In this panel session we will discuss this question focusing on different aspects. To what extent are researchers in medical ethics useful for the clinic and for policy? Any good examples? If so, what is useful and, perhaps more importantly, what is not useful? If medical ethics is not directly useful, is there still a role for it in terms of being a "basic science"? In the panel our two plenary speakers Silke Schicktanz and Leonard Fleck will represent the academic side of medical ethics, Marit Karlsson, MD and palliative care physician at Region Östergötland will represent the clinic and Martin Henriksson, senior associate professor in health economics and part of the board of The Dental and Pharmaceutical Benefits Agency, will represent the policy level.

SPEAKERS

Neurotechnologies: Ethical and Human Rights Lens

Jonathan Andrew, Kristina Hug

Neurotechnologies constitute a fast-evolving field of measuring, analysing, and potentially modifying activities of the human nervous system. They include devices and capabilities such as neuroprostheses, neuromodulation and brain-machine interfaces. In medical and non-medical fields, they may have profound implications for fundamental human experiences, potentially transforming notions of identity, autonomy, privacy, and cognitive agency. Given such potential, their use raises ethical issues, e.g. boundary-drawing and harm-benefit balancing. Whilst public debate over neurotechnologies has highlighted concerns, frequently less prominent in the ethical and legal discourse have been their potentially profound positive impacts. Neurotechnologies may radically improve quality of life for marginalised and minority groups and provide broader possibilities for the enjoyment of human rights often affected by health-related limitations. We examine how to improve these possibilities and analyse what novel, yet foreseeable challenges they present for affected stakeholder groups. We discuss different neurotechnology-based treatments (e.g. for Parkinson's or chronic pain) and analyse what novel, yet foreseeable challenges such treatments present for affected stakeholder groups. How might neurotechnologies affect representation, autonomy, or the privacy of marginalised groups, people with functional diversity, or the severely ill? Given the EU regulations and international conventions, our work elucidates the ethical and legal boundaries of neurotechnologies and their justifiability from the perspective of affected stakeholders. Our work constitutes the first step of a broader task. Given existing EU regulations and international conventions, it elucidates the ethical and legal boundaries of

clinical neurotechnology applications and their justifiability from the perspective of affected stakeholders. It examines how fostering patient engagement through appropriate consultative mechanisms can facilitate the reconciliation of competing values. Given fast-paced scientific advancement, the discourse on neurotechnologies must be informed by stakeholder perspectives (our next empirical step). Absent this engagement, insights into whose, and which, interests (e.g. cognitive autonomy, accessibility, equality of access, cultural and social acceptance) are at risk. Moreover, conflicting values may also require resolution so as to ensure neurotechnologies reach their full potential.

Doing or Talking? Unexplored Challenges in Priority Setting

Joar Björk

Healthcare resources are limited, and from the micro level of a patient's bedside to the macro level of drawing up medical guidelines, difficult priority setting decisions need to be made so that resources are distributed in a way which is fair and efficient. At its easiest, priority setting decisions relate to using one or another medical intervention to treat one particular medical condition. Trickier questions may involve how to prioritize between interventions aiming at different kinds of medical benefit, such as pain relief versus longevity, or interventions with curative intent versus interventions with preventive intent. A further priority setting conundrum, which has been largely unexplored, concerns the trade-off between, on the one hand, medical *interventions* and, on the other hand, medical *communication*. Obviously, the division is not clear-cut as most medical interventions require some form of communication. Nonetheless, clinical reality is full of situations where healthcare staff have to decide whether to spend a particular unit of time on the execution of a medical task, or on (more) communication with their patients.

Although Sweden has, by international standards, an unusually well developed framework for making priority setting decisions (the Swedish "Ethical platform for priority setting"), this framework provides insufficient guidance for staff to adjudicate between interventions and communication. Indeed, patients' access to interventions and to communication is partly treated, in Swedish government white papers, using different languages of governance as interventions should be distributed according to medical need, whereas medical communication is framed as something which healthcare staff is obliged to provide without consideration of (the degree of) medical need.

The current project has several separate but related aims. The first is to describe what (if anything) current Swedish law and white papers can be taken to say about the prioritization of interventions vis-à-vis communication. The second is to describe, empirically, how healthcare staff understand and deal with this priority setting conundrum. The third is to investigate, normatively, how the conundrum ought to be settled. This will be done, mainly, with reference to the values already in the Swedish Ethical platform, but also with an eye to the international priority setting discussion and to to values and principles conventionally accepted within modern medical ethics.

The proposed presentation for LIMEC will touch briefly on the first and second aims of this project and focus on the third aim. Three possible approaches to the question of "doing or talking" will be presented, and a modest proposal will be made.

Self-Ownership and the Moral Significance of Birth

Greg Bognar

According to a common view, abortion becomes increasingly morally problematic in later stages of pregnancy. Late-term abortions require more momentous moral justification. This, however, is thought to create a problem: other things being equal, whatever reasons justify late-term abortions, they justify the killing of newborns as well. If the only difference between a late-term fetus and a newborn is their location, then the moral difference between abortion and infanticide cannot be maintained.

This is a well-known problem for permissive views on abortion. It is widely accepted that birth itself has no moral significance. In this talk, I challenge this consensus. I argue that there is a morally significant difference between a fetus and a newborn: the newborn acquires self-ownership at birth. This changes the balance of reasons: everything else being equal, killing a newborn is morally more problematic than killing a fetus. Permissive views can, after all, maintain the moral difference between abortion and infanticide.

Rule of Rescue and Funding Drugs for Rare Diseases

Kenneth Bond

Decisions about how to best allocate health care resources can be controversial, perhaps none more so than decisions concerning high-cost drugs for rare diseases (DRDs). Many DRDs are priced significantly higher than drugs and other health technologies that treat more common, but equally serious, conditions. With a rapidly growing number of DRDs being marketed and in development, there is the potential for DRDs to impose a significant opportunity cost on publicly funded health care systems. Many countries' health care systems implicitly or explicitly prioritize DRDs based on a perceived moral obligation to save small numbers of people whose lives are imminently threatened, an obligation that has been referred to as the "rule of rescue" (RoR). While there are various formulations of the RoR, many health economists and moral philosophers are skeptical that a plausible version of the RoR can be formulated for health policy. It appears, then, that an unresolved tension remains between the belief that the RoR provides a normative justification for prioritizing DRDs and the ability to find a well justified mid-level formulation of the RoR for prioritizing DRDs. This paper addresses three main shortcomings of previous examinations of the use of the RoR for health care resource allocation decisions.

First, many previous definitions of the RoR within the context of health care resource allocation have been based on clearly objectionable assumptions, such as that the RoR obligates us to rescue at all costs or applies to only "identifiable" victims. We offer a policy formulation of the RoR (hereafter, the "institutional rule of rescue" or iRoR) that avoids these assumptions and that provides a more reasonable characterization of the RoR for policy, one that coheres with both relevant moral principles and our moral intuitions regarding rescue. Second, the RoR is often characterized as a "deontological imperative" because of its ability to override the welfare maximizing policy conclusions of traditional cost-effectiveness analysis. However, there have been few thorough examinations of the range of non-consequentialist approaches that may provide a ground for the RoR and its application to health care policy. We examine the ability for several previously neglected approaches and principles to support the iRoR: social contract theory (as articulated by John Rawls and Thomas Scanlon), virtue ethics, solidarity, non-abandonment, and perfect duties. We argue that contract theory, virtue ethics, and perfect duties are the most promising candidates for justifying the iRoR.

Nevertheless, the iRoR will not justify prioritizing DRDs as a distinct class. Third, if there is no plausible ground for the iRoR, there may be other well-established high-cost medical rescue services and programs the priority for which might also be questioned. We describe a number of these services and argue that, if the iRoR is their most plausible justification, we ought to examine the most promising grounds more carefully for the iRoR to ensure our health care resource allocation decisions are both morally justified and financially responsible.

Moral Distress among Emergency Department Staff

Clara Brune, Pernilla Lundmark, Lotta Nylén, Bo Burström, Johan von Schreeb, Ann Liljas

Moral distress, a present work environmental challenge in emergency departments (EDs), describes a reaction to being constrained from acting in accordance with one's values. This study explores causes, consequences, context and coping of moral distress among ED staff, offering interprofessional insights to inform interventions and support organizational improvement. Thirty-six healthcare staff from two EDs in Region Stockholm, Sweden, participated. Seven interprofessional focus group sessions with doctors, nurses and assistant nurses were carried out. Focus groups were recorded, transcribed and analyzed using reflexive thematic analysis. The overarching theme generated through the analysis was *Moral distress – A normalized part of fulfilling the mission*. Eight subthemes and 41 codes were identified. Reported causes of moral distress included managing a lack of hospital beds, long waiting time, and insufficient staffing. Participants reported an intensified need to prioritize, working with lacking resources and high demand, difficult decision-making, team-based challenges, lack of control and organizational obstacles. Overall, participants reported feeling insufficient in their roles to manage the demands placed on them. Reported consequences of moral distress included worsened well-being with an influenced self-image, and experiencing conflicts between personal life and work, forming a vicious cycle which contributed to a will to quit working. Participants reported on various coping strategies on both an individual-, group- and workplace level to manage moral distress. They mainly relied on informal support from colleagues but were restricted to do so due to heavy workload and time constraint. They requested access to structured ways to manage moral distress, both in terms of debriefings, check-ins, individual support and closer manager contact. Access to more resources to enable such support structures were considered fundamental. Participants further highlighted several organizational and systemic areas of improvement which they considered could prevent moral distress. These included having adequate access to hospital beds, and adequate staffing. In conclusion, this study sheds light on potential areas of improvement in supporting staff to manage their work, and on the healthcare system through participants' suggestions. These are relevant for staff well-being, organizational resilience, and patient care outcomes.

Justifying the Principle of the Best Interest of the Child

William Bülow

It is widely assumed that we have special duties towards children. This is most evidently so if we consider the moral claim that, in any decision concerning children, the best interest of the child should be a *primary* consideration (see, e.g., Archard et al. 2024; Deikeman 2004;

Bester 2019; UN Convention on the rights of the child). This principle, henceforth the principle of the best interest of the child (BIC), is widely recognized and applied in different areas, not least in health care and in social work and family care.

Intuitive as it is, it is unclear what justifies this principle. After all, also the opposite might be taken to be intuitive – that need and ability to benefit should count equally regardless of who has the need or the ability. This would go against that anyone should be (given) a primary consideration. So, what is it, exactly, that provides children with a special moral status such that their interest should be a primary consideration? Why should their interest be given priority over the interests of others?

Surprisingly, this question has gained very little attention in the field of health care ethics. In this debate, focus has rather been on the nature of the principle, its scope and relative strength (Archard et al. 2024; Kopelman 2018; Salter 2012; Wilkinson 2019).

On one interpretation, explicating the most reasonable interpretation of BIC is part of justifying the principle in accordance with a coherence theory of justification. Following the method of reflective equilibrium, some may insist that the most plausible interpretation of BIC is the one that cohere with our considered moral judgements. But even so, we believe that a more robust justification should also provide an explanation of why the child's best interest should be a primary consideration. To this end we distinguish and assess four possible reasons why the best interest of the child should be a *primary* consideration in ethical decision-making concerning children. First, children are innocent and have done nothing to deserve to suffer harm. Second, children are inherently vulnerable and dependent on others. Third, some harms, if caused during childhood, is irreparable during adulthood. Forth; satisfaction of children's interest has a greater value in a Millian consequentialist sense. Of these different reasons, we argue that of these the second and the third are the most promising. Jointly they may provide a role-specific explanation as to why the best interest of the child should be a *primary* consideration in decision-making concerning children.

References

Archard, David., Cave, Emma & Joe Brierley (2024). How should we decide how to treat the child: harm versus best interests in cases of disagreement. *Medical Law Review* 32, 158-177.

Kopelman, Loretta M. (2018). Why the Best Interest Standard is Not Self-Defeating, too individualistic, Unknowable, Vague or Subjective. *American Journal of Bioethics* 18(8): 34-6.

Salter, Erica K. (2012). Deciding for a child: a comprehensive analysis of the best interest standard. *Theoretical Medicine and Bioethics* 33(3): 179–198.

Wilkinson D. In defense of a conditional harm threshold test for paediatric decision-making. In: Goold I, Herring J, Auckland C, editors. Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates. Oxford (UK): Hart Publishing; 2019.

Clinical Ethics and Policy: A Case Study of Björn Nordenström's Theory and Therapy in Cancer Treatment

Anne Chang

The case study is of the discussion regarding clinical ethics, policy, as well as the new medical science and technology applied in clinical practice. It explores the cooperation of Swedish

and Chinese researchers around the theory of *Biologically Closed Electric Circuits (BCEC)*, created by Swedish medical scientist Björn Nordenström, and its adjunct clinical application, *Electro-Chemical Therapy (EchT or ECT)*. BCEC was, and is, a novel theory in medical science which explore and explain the movement of electricity in the human body outside of the nervous system. The treatment for a group of 22 lung cancer patients using BCEC method was implemented at the Department of Thoracic Radiology at Karolinska University Hospital between 1978 and 1981. It had experienced obstruction in Sweden due to lacking of Randomised Controlled Trial (RCT) after 1981. However, EchT was approved to be used by the Ministry of Health of China widely in China as an effective, low-cost treatment for cancer since 1987. Roughly 13000 Chinese cancer patients were treated using EchT and survived between 1987 and 1990. It was contained in China's national healthcare insurance system since 1996.

The purpose of this qualitative case study is to discover how the interaction of clinical ethics, the standard in clinical research and practice - RCT, and policy making affect clinical application of the new medical scientific technology for cancer treatment in both Sweden and China in 1980s. RCT has been viewed as the golden standard in modern clinical research and practice for adopting a new treatment method from clinical ethics perspective. However, the application of EchT in cancer treatment in China differed with Sweden because of the policy making based on different considerations even though lacking of RCT test.

The case study adopts normative methodology approach by conducting experts interview both in China and Sweden and the first hand materials collected from Björn Nordenström's house to analyse the phenomena and to fill the research gap in this field. The research framework is designed based on *'Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine'* written by Albert Jonsen, Mark Siegler, and William Winslade.

Nordenström was a prominent member of the Nobel Committee for Physiology or Medicine and the Chairman in 1985. Instrumental to the re-adaption of EchT to local clinical demands was his close cooperation with Dr. Yuling Xin, the pioneer thoracic surgeon in China. Xin's efforts made the impact of decision of policy making in cancer treatment in China although lacking of RCT test of using EchT technology which could be a potential clinical ethics conflict.

Clinical ethics is an inherent part of clinical medicine since the physician has an ethical obligation to benefit the patient. The successful application of EchT in cancer treatment in China without RCT test reflects that making flexible policy in clinical practice can make positive impact considering patients' benefit when confronting urgent demands.

Medical Ethics and Politics

Göran Collste

The Swedish National Council on Medical Ethics (Smer), was founded in 1985. The council is an advisory board to the Swedish government and parliament on ethical issues in biomedicine. The council shall stimulate exchange of information and ideas and promote discussion on new medical research and applications. Smer is an independent authority but administratively connected to the Swedish government.

Members of the board include a chair, representatives of eight major political parties and 10-15 experts in medicine, law and ethics. In this way it differs from other ethics councils, like for example the British Nuffield Council and the German Ethics Council, that have only expert members but no representatives of political parties.

In my presentation I will discuss two questions related to the role of ethics and ethicists in Smer.

What is the role of ethicists in Smer?
Are there ethical experts, similar to experts in medicine and law? An expert is someone who has deep knowledge in an area, that others, non-experts lack.[1] From an expert in ethics you can expect competence in identifying relevant norms and principles, analytical skills and knowledge of ethical theories. However, it is less clear that the ethicist can give expert guidance on normative issues. Our views on what is right or wrong is based on experience and world views. Even if ethicists normally have reflected more than others on moral questions and moral dilemmas, this does not necessarily provide them with the moral sensitivity and virtues necessary for a good moral agent.

What are the possibilities and problems with an ethics board with both politicians and expert members?
The political representatives in Smer enables a link between medical ethics and political decision making. The political members are usually either members of parliament or political leaders of medical health authorities. Therefore, they can both initiate relevant ethical issues to Smer and provide channels for Smer to influence political decision-making on national and regional levels.

However, although many controversial questions in medical ethics, like abortion, euthanasia and reproductive medicine are not political *per se*, other ethical questions like for example the provision of health care for refugees and persons without permanent residence, and the implication for equity of privatisation of health care are politically controversial.[2] There is a risk that Smer evades controversial questions in order to avoid political conflicts in the board.

Incidental Findings in Metastatic Breast Cancer Care: Ethical Reflections

Jasper Debrabander

In this talk, I will argue that metastatic breast cancer patients should receive the opportunity to opt-out of incidental findings of low clinical utility that arise during treatment response monitoring.

In a clinical context, incidental findings can be defined as findings that are beyond the original indication of a test or procedure. In the case of treatment response monitoring for metastatic breast cancer, the original indication is to monitor how the patient's breast cancer responds to her treatment. All findings that are unrelated to her breast cancer are therefore

[1] For a discussion on ethics expertise, see: Expertise, Ethics Expertise, and Clinical Ethics Consultation: Achieving Terminological Clarity, Ana S Iltis 1,2,*, Mark Sheehan J Med Philos. 2016 Jun 2;41(4):416–433. Debating Ethical Expertise, Norbert L. Steinkamp , Bert Gordijn , Henk A. M. J. ten Have, Kennedy Institute of Ethics Journal, Johns Hopkins University Press, Volume 18, Number 2, June 2008, pp. 173-192

[2] https://smer.se/2020/11/23/vard-av-personer-utan-permanent-uppehallstillstand https://smer.se/2022/02/03/remissvar-reglering-av-privata-sjukvardsforsakringar-okad-kunskap-och-kontroll-sou-202180/

incidental. For example, when a lesion in the thyroid is identified, this constitutes an incidental finding.

At present, metastatic breast cancer patients are predominantly monitored by way of CT scans and are not given the opportunity to opt-out of any incidental findings. However, the increased adoption of PET-CT as the standard of care might challenge current practice. For although the present evidence indicates that PET-CT is more accurate for treatment response monitoring purposes than CT in the context of metastatic breast cancer, it also yields a higher number of incidental findings. Moreover, the possibility that these incidental findings result in psychological harm as well as physical harm due to futile further testing is more than real given the high false positive rate. Although the medical community is acutely aware of these complications of PET-CT, the present opt-out policy has not been reconsidered.

Fiduciary duties are professional duties physicians have to act in the best interest of their patients. These duties drive current practice regarding the disclosure of incidental findings in metastatic breast cancer care. Physicians disclose all and only incidental findings that they take to be in the best interest of the patient. The patient has no say regarding when the disclosure of an incidental finding is in her best interest. However, on the basis of their right (not) to know, patients might challenge the status quo.

I will argue for two claims. (i) Patients should not be given the opportunity to opt-out of incidental findings that are of high clinical utility. For example, a lesion in the colon that strongly suggests a synchronous colon cancer should be disclosed. The reason is that these incidental findings lie beyond the scope of the right not to know in the context of treatment response monitoring. The dominant, but contested justification of the right not to know is autonomy. In order to remain autonomous regarding one's ongoing treatment, the patient needs to be informed about incidental findings that offer a reasonable person a significant reason to reconsider her ongoing treatment. I will theoretically justify this position in relation to literature on an evidence-responsiveness condition for autonomy. Therefore, autonomy does require the disclosure of these findings and cannot simultaneously ground the right not to know. (ii) Patients should be given the opportunity to opt-out of incidental findings that are of low clinical utility (e.g. lesions in the thyroid). In those cases, patients' right not to know does apply and plausibly outweighs physicians fiduciary duties.

A Conceptual Analysis of the Currency for Severity

Adam Ehlert

When making decisions about distribution of health care resources, it is increasingly common to rely on some notion of severity, where one claims that more of scarce resources should be distributed to patients with more severe conditions. There is broad public support for such a principle, and it has been implemented in different forms in several health care jurisdictions. However, the concept of severity is notoriously under-defined, and is operationalized in different ways across different health care systems. Since severity seems to carry a substantial moral weight, it is therefore important to further clarify both the concept itself and its underlying normative rationale (Barra et al. 2020). In this paper, I attempt to provide a conceptual analysis of severity (used as a priority setting criterion in health care).

I use a dimensional method of conceptual analysis, similar to that used by for instance Brülde (2000) and Bradley (2012), where I set out a number of conditions of adequacy for the concept and test different notions against these conditions. I argue that a notion of

severity should be simple, reliable, precise, theroetical, value-based and in accorrdance with ordinary language. I test the ”gold-standard” currency of Health-Related Quality of Life, as well as notion such as suffering, prognosis, disabilitty and existential need, against these conditions.

References:
Barra et al. (2020). Severity as a priority setting criterion — setting a challenging research agenda. Journal of Medical Ethics.
Brülde (2000). On how to define the concept of health. A loose comparative approach.
Bradley (2012). Doing Away With Harm.

Predicting Patient Choice and Preference

Kalle Grill, Erik Campano

A main topic in medical ethics is the tension between physician benevolence and patient autonomy. Recent technological advances provide new methods for bolstering both these values. Diagnosis and treatment recommendations can be improved by clinical decision support systems (Lorenzini et al., 2023). Patient understanding can be informed by machine-supported information, including visual aids and interactive tools (Sutton et al., 2020). When patients incapacitated, their preferences can be deduced by *patient predictor systems* - algorithms based on their sociodemographic characteristics along with their previous decisions, behavior, and stated preferences (Rid & Wendler 2014; Ferrario et al., 2022).

Recent ethical discussion of patient predictor systems lacks clarity in several dimensions. Scholars do not distinguish adequately between choices and preferences, between different senses of preference, nor between choice and preference for treatments versus choice and preference for decisions procedures for treatments. For example, Earp et al. (2024) speak interchangeably about what the patient "would choose", what she "would want", what her preferences are, and what her values are.

In order to be respectful of patients, these things should be distinguished and spelled out. Choices are explicit decisions, manifest in action or communicated or recorded, and so social and performative. Preferences are mental states, or, more specifically, comparative evaluations. We hold that respect for people as both agents and evaluators requires respect for both their choices and their preferences.

We distinguish between three senses of preference. S*ituational preferences* are occurrent mental states that typically precede choices. They are based on our assessment of the situation, including our current and occurrent beliefs and desires. *Overall preferences* are what we would situationally prefer if we methodically and rationally considered the nature and consequences of the relevant alternatives and how they would align with all of our beliefs and desires. *Authentic preferences* are based only the subset or our desires that we experience as central to our identity and most important aspirations. This centrality can be spelled in analogy to different theories of autonomy, such as higher order endorsement (Frankfurt 1971), overlap with judgments about what is good (Watson 1975), or stability in the face of counterfactual stress testing (Christman 1991).

The three senses of preference will often point in different directions. It is common to be prepared to choose one thing, while thorough consideration of all of one’s beliefs and desires would lead one to choose another thing, and consideration of only one’s most central

or otherwise fundamental preferences would lead one to yet another choice. Argument for patient preference predictors should be clear on what is predicted or estimated. Current literature is focused on predicting health outcomes on the one hand and patient preferences regarding treatments on the other. However, we may use predictor systems also to estimate preferences over decision procedures, as well as estimate the existence and content of potential antecedent choices for treatments or for decision procedures. Furthermore, what predictor technology we invest in will affect what uncertainties are reduced and so what factors get to play a larger role in these difficult and important decision.

References

Christman, John. "Autonomy and Personal History." Canadian Journal of Philosophy 21, no. 1 (1991): 1–24.

Earp, Brian D., Sebastian Porsdam Mann, Jemima Allen, Sabine Salloch, Vynn Suren, Karin Jongsma, Matthias Braun, et al. "A Personalized Patient Preference Predictor for Substituted Judgments in Healthcare: Technically Feasible and Ethically Desirable." *The American Journal of Bioethics* 24, no. 7 (July 2, 2024): 13–26.

Ferrario, Andrea, Sophie Gloeckler, and Nikola Biller-Andorno. "Ethics of the algorithmic prediction of goal of care preferences: from theory to practice." Journal of medical ethics 49, no. 3 (2023): 165-174.

Frankfurt, Harry G. "Freedom of the Will and the Concept of a Person." The Journal of Philosophy 68, no. 1 (1971): 5–20. https://doi.org/10.2307/2024717.

Lorenzini, Giorgia, Laura Arbelaez Ossa, David Martin Shaw, and Bernice Simone Elger. 2023. "Artificial Intelligence and the Doctor–Patient Relationship Expanding the Paradigm of Shared Decision Making." *Bioethics* 37 (5): 424–29.

Rid, Annette, and David Wendler. "Use of a patient preference predictor to help make medical decisions for incapacitated patients." Journal of Medicine and Philosophy 39, no. 2 (2014): 104-129.

Sutton, Reed T., David Pincock, Daniel C. Baumgart, Daniel C. Sadowski, Richard N. Fedorak, and Karen I. Kroeker. "An overview of clinical decision support systems: benefits, risks, and strategies for success." NPJ digital medicine 3, no. 1 (2020): 17.

Watson, Gary. "Free Agency." *The Journal of Philosophy* 72, no. 8 (1975): 205–20.

Getting the Ethics of Medical AI Right

Madeleine Hayenhjelm

How do we get the ethics right for AI in the clinic? What would it require to get the ethics right from the beginning? In this talk I will argue that these are precisely the kinds of questions we will need to ask. I shall argue that neither the traditional mid-level biomedical ethical principles of Beauchamps and Childress nor the newly developed AI ethical frameworks, such as the Framework for Trustworthy AI, are satisfactory—at least not without additional work. The former option is too narrow in scope. If AI raises more political questions than those typically addressed in medical ethics, as Vèliz suggests, or if AI has the potential to transform our existing medical practices, as Rubeis argues, we will need to look beyond the individual patient and ask other kinds of ethical questions as well. The latter option has other kinds of problems, most of which has to do with theoretical weaknesses of the guidelines themselves. There are conceptual ambiguities, lack of attention to conflicts between principles, and an overall lack of justification for moral principles. Overall, there

seems to be both too many guidelines and too many principles, as if the idea what to find a "moral principle" to match each moral concern.

In this talk I will point in two directions for future guidelines on AI ethics. What the existing general AI ethical guidelines lack is a firm rooting in moral fundamental theory. The principles are more often imported "horizontally" than from other guidelines, including medical ethics, than normative theory. However, this atheoretical approach leave the principles without clear justification and without any clear distinction between principles based on fundamental moral considerations and merely instrumental ones. In this regard, the biomedical ethical principles are on a much stronger footing. Here the challenge is that the moral fundamentals have already been specified and given a narrower meaning that the core concept implies. This specification may not the most optimal one for medical AI. What the current biomedical ethics principles do not provide, however, is a systemic approach to map potential issues, contexts of use and abuse, and relevant affected parties (both moral agents and moral patients) relevant for the development and use medical AI across the relevant domains. Traditionally, moral theory has been assessed against two measures: moral truth and action-guidance in a very theoretical sense. I shall argue that will need something weaker than moral truth (given moral uncertainty) and something richer than action-guidance in a merely theoretical sense based both on moral norms and the relevant contexts of use.

References

Beauchamps, T. & Childress, J. (2019) *Principles of Biomedical Ethics*, 8th ed. Oxford: Oxford University Press.

Corrêa, N. K., Galvão, C., Santos, J. W., Del Pino, C., Pinto, E. P., Barbosa, C., ... & Terem, E. (2022). Worldwide AI Ethics: a review of 200 guidelines and recommendations for AI governance. *arXiv preprint arXiv:2206.11922*.

Floridi & Cowls (2019) "A Unified Framework of FivePrinciples for AI in Society" Harvard Data Science Review 1(1): 4.

Hagendorff (2020) "The Ethics of AI Ethics: An Evaluation of Guidelines" *Minds and Machines* (2020) 30: 103.

Hagendorff,

HLEG *Ethics Guidelines for Trustworthy AI* (EC 2018, 2019).

Prem, E. (2024) "Approaches to Ethical AI", *Introduction to Digital Humanities*.

Rességuier, Anais & Rodrigues, Rowena (2020) "AI ethics should not remain toothless! A call to bring back the teeth of ethics", *Big Data & Society* (July-December 2020): 1-5. L.

Segers, S and De Proost, M. (2024) "Take five? A coherentist argument why medical AI does not require a new ethical principle" *Theoretical Medicine and Bioethics* 45: 387-400.

Ursin, F., Timmerman, C, Steger, F. (2022) "Explicability of artificial intelligence in radiology: is a fifth bioethical principle conceptually necessary?", *Bioethic*s, 36: 143-153.

Veliz, C. (2019) "Three things digital ethics can learn from medical ethics," *Nature Electronics*, www.nature.com/natureelectronics.

Whittlestone et al. (2019) Ethical and societal implications of algorithms, data, and artificial intelligence: a roadmap for research. London: Nuffield Foundation.

Downsides of Handling Research Ethics by Law

Gert Helgesson

The introduction of law to regulate ethical aspects of research has been welcomed, by some, as a replacement of a reactive tradition of "progress by scandals" with a more proactive approach to the handling of research ethical issues. However, releasing legal regulation into the domain of research ethics has introduced a new set of difficulties, some of which are clearly disturbing.

One potential problem with the "legalization" of research ethics is that ethics and law get *conflated*. A further step down that road, ethics is *reinterpreted* as law, so that there are no perceived ethical issues apart from the legal issues relating to research. Legal regulation also introduces alternative understandings of what values are at stake, and their relative significance, that in parts appear arbitrary from an ethical perspective.

With the introduction of a Swedish law in 2020 (Act 2019:504) making some forms of scientific misconduct illegal, another difficulty has been added: law reuses research ethical terms, but change their meaning, thereby creating a self-inflicted conflict between legal and research ethical interpretations of long-used terms. Furthermore, there is sometimes a failure, in legal practice, to see that with change of interpretation might come a change in the seriousness of the offense.

This presentation aspires to give a brief overview of the difficulties introduced by legal regulation of research ethics and provides the example of the handling of "the corresponding author" in a recent legal case, to underline the present arbitrariness of Swedish legal practice in this area.

Intercontinental Research and Ethics Advisory Role

Kristina Hug, Jonathan Andrew

Dengue pandemic preparedness requires collaboration across both disciplinary and continental boundaries, involving countries with different levels of economic development and diverse legal frameworks. Dengue, initially confined to tropical and subtropical areas, is now an increasing public health threat in Europe, with risks of transmission extending year-round due to climate warming (favourable for the proliferation of Dengue-transmitting mosquitoes). Dengue causes around 10,000 deaths and 100 million symptomatic infections annually across more than 141 countries with more than €8 billion in annual global costs. Assisting Dengue pandemic preparedness through the EU-funded COMBAT project, global research engaging multiple legal jurisdictions and diverse local practices engages challenging ethical and legal complexities. Certain COMBAT tasks are to create tools to prevent severe Dengue which requires hospitalization (and thus significant resources) that leads to long-term neurological complications. The COMBAT project efforts require collaboration across disciplinary and continental boundaries – the latter to learn from Dengue endemic regions, such as Central America (Guatemala) and South-East Asia (India) and apply the data and clinical material collected there for research conducted in European facilities. These activities inevitably raise complex issues of both an ethical and legal nature and require ethicists and lawyers to build teams around joint assignments, since one type of expertise does not suffice in the light of the complexity involved. Our discussion analyzes the ethics advisory role in such intercontinental collaborations and the facilitation of research counteracting emerging pandemics. The study draws upon COMBAT's experiences and presents a planned survey of Consortium members on

the ethics support requirements expected by scientists. It reviews how this support can best be delivered and provides insights benefitting future research projects of similar complexity.

Ambivalence and Autonomy

Ulrik Kihlbom

Assume there is a decision to be made regarding whether and how an 11-year-old child in social care should have contact with their biological parent. The child clearly expresses ambivalence to the social worker, who is also the decision-maker. On the one hand, the child wants to remain loyal to their parent and maintain contact. On the other hand, they are worried that social contact may be distressing due to the parent's past behaviour.

According to Swedish law, the best interests of the child must be the primary consideration in all decisions involving children in both social care and health care. Assessing the child's best interests when deciding whether to restrict their right to socialization with their parent or legal guardian presents an ongoing and difficult challenge for social workers. Preliminary results from an empirical study suggest that determining how to proceed when a child expresses ambivalence is a pressing problem for social work professionals making decisions about social contact.

The questions I will discuss in this paper are:

1. Should a child's will, based on loyalty, be considered a proper factor in assessing the child's best interests?
2. Are loyalty concerns distinct in ways relevant to the decision-making context described above?
3. Is paternalism, in cases like the one described above, more justified when addressing solidarity-based expressions of will than when addressing more self-directed concerns, such as well-being?

I will argue that all of these questions should be answered affirmatively, albeit with some important qualifications.

The Therapeutic Misconception and Hermeneutic Injustice

Naja Rathje Lennert

The therapeutic misconception is an epistemic phenomenon that can affect people participating in experimental medical trials. The term itself assigns responsibility either to the research-subject or to the researcher, for either not informing well enough or not understanding the information well enough. While some attention has been given to the ways this phenomenon not only affects understanding, but also trust (De Melo-Martín & Ho, 2008), I will argue that not enough attention has been paid to the context of the problem. Therefore, I suggest that using a framework of hermeneutic injustice inspired by José Medina (Medina, 2013a), can help us understand the full scope of the problem.

The term “Therapeutic Misconception” was coined by Appelbaum et al in 1982, (Appelbaum et al., 1982). It denotes the misconception that research subjects might fall under, when they move from being patients to research-subjects. Here it is possible that they

conflate the research being done on/with them, with treatment. While much research has been done on the influence of informed consent, including different ways of informing and different types of consent (Appelbaum et al., 2012; Caulfield & Murdoch, 2017; De Melo-Martín & Ho, 2008; Eeckhout et al., 2023; Ploug & Holm, 2016), there seems to be an approach that has yet to be used in its full potential: trying to understand the problem as an instance of hermeneutic injustice. I will be arguing that the way informed consent has ended up being used in the transition from patient to research-subject can constitute a hermeneutic injustice. I will examine the therapeutic misconception, shed light on how hermeneutic injustice-theory can help inform what is at play, and how we might try to ameliorate the trouble already caused. I will draw inspiration from José Medina's work on hermeneutic injustice (Medina, 2013b), to illuminate the multifaceted problems that the therapeutic misconception covers. Finally, I will argue that using the framework of hermeneutic injustice when examining the therapeutic misconception is constructive to the further examination and use of the term therapeutic misconception. This is because, rather than assigning responsibility for the lapses of informed consent to either the recipient of the information or the elicitor of consent, it shows that it is the way in which informed consent has become a bureaucratic tool rather than an ethical loadstone that bears responsibility for the development of the misconception.

Suicide Risk Assessment can be Understood as Medical Rituals

Antoinette Lundahl

The use of suicide risk assessments in individual psychiatric treatment is widespread and, in many countries, mandatory. However, these assessments exhibit poor predictive accuracy and offer limited clinical value. This raises the question of whether non-medical reasons underpin their continued use. In this paper, suicide risk assessments are interpreted as medical rituals—formalised, repetitive behaviours imbued with symbolic significance that fulfil social functions. Several such functions are proposed, including uniting care providers around shared values in suicide prevention, fostering a sense of safety and control over suicidal behaviour, projecting accountability, and signalling to the public that action is being taken.

However, this practice may inadvertently lead to an increase in non-beneficial compulsory admissions, flawed prioritisation of patients, and the proliferation of defensive medicine. While the ritualistic use of suicide risk assessments may serve important societal purposes, their potential to harm individual patients renders them indefensible from a medico-ethical standpoint. Instead, evidence-based suicide preventive interventions are recommended. These include implementing general safety measures, equipping psychiatric patients with safety plans, and providing effective mental health treatment according to medical needs.

Rethinking the Right to Withdraw in Individualized Therapy Development

Mariia V Maksimova, Ghislaine J M W van Thiel, Rosan Lechner, Johannes J M van Delden

Individualized therapy development (N-of-1) for patients with ultra-rare diseases places the traditional understanding of the right to withdraw under pressure. The traditional understanding of this right as complete, immediate, and unconditional is not always feasible

when the therapy development process is built around one patient (or very few) and depends on them at almost every stage. This traditional understanding of the right to withdraw may conflict with the mutual dependence of researchers and the patient, the substantial resources spent to develop a therapy for one patient, and the social value of knowledge gained in the process. Starting from the case of Milasen, the first FDA-approved single-patient antisense oligonucleotide (ASO) therapy, we reconstruct the typical patient journey in ASO-based therapy development – a widely used approach for ultra-rare genetic diseases. We show how aspects relevant to the interpretation of the right to withdraw are changing dynamically through various phases of the patient journey in individualized therapy development: from blood drawn to personalized disease model creation to therapy administration and follow-ups. We distinguish four ethically relevant aspects for the understanding of the right to withdraw:

- the degree of the patient's bodily involvement;
- uncertainty about risks and benefits;
- mutual dependence between patient and researchers;
- and the intensity of resource use.

With those aspects evolving, the interpretation of the right to withdraw takes on different meanings. We propose a phase-dependent (or dynamic) approach that shapes withdrawal as an ongoing dialogue, allowing exploration of patient perspectives and motivations and balancing patient autonomy with the social and scientific value of individualized therapy research. Such an approach turns the concept of the right to withdraw into an avenue for patient engagement and early addressing concerns, preventing withdrawal from becoming a crisis.

This research is funded by ZonMw (The Netherlands Organisation for Health Research and Development) through the TAILORED project: Toward a human iPSC neuronal platform for neurodevelopmental disorder therapeutic discovery, project number 10250022110002 (2021-2026).

The Reversibility of Deep Brain Stimulation in Decision-Making

Lukas J. Meier

Some medical interventions have the potential to interfere with patients' decision-making. In this talk, I identify two types of such influences: affecting whether a patient has decision-making capacity in the first place; and influencing which treatment option a patient ends up selecting.

Medical interventions differ in whether their psychotropic modifications are reversible, and – if reversible – in the time span required for the reversal to manifest. Using the example of deep brain stimulation, I argue that where the reversibility of psychotropic effects is comparatively quick, one should utilise this effect to enhance decision-making capacity and to obtain more authentic treatment preferences than currently employed procedures deliver. Consequently, in patients with implanted deep brain stimulators who do not meet the capacity threshold with regard to a particular treatment decision, the device status should be reverted (switched off, if previously activated; switched on, if previously deactivated) as there is a small chance that doing so has a positive effect on their capacity.

In patients who are already deemed decision-competent, the same procedure can reveal potential on/off-discrepancies: fluctuations in the selection of treatment plans depending on whether the neurostimulator is activated or deactivated. Which choice should be regarded as the definitive one – the treatment plan selected when the stimulator is on, or the intervention picked when the device is off?

I will outline five different strategies that clinicians could employ to elicit authentic decisions from patients in the face of such on/off-discrepancies: (1) prioritising the preference obtained when the device is in the regular state; (2) prioritising the latest decision obtainable; (3) prioritising the earliest decision obtainable; (4) confronting the patient with reasons they provided in the opposite device state; (5) redesigning, if possible, the treatment offers until the on/off-discrepancy can be eliminated. All of these approaches have significant advantages and disadvantages, which I shall explore, and which we can discuss during Q & A.

While on/off-discrepancies are most easily uncovered in deep brain stimulation, I will be calling for a general reconsideration of decision-making procedures following any interventions whose psychotropic influences can be reversed within clinically reasonable time frames – to strengthen patient autonomy and increase the authenticity of medical preferences.

The Tragedy of Positive Reproductive Rights: Policy Dilemmas and the Promotion of Family Diversity

Francesca Miccoli

Reproductive freedom is often framed in terms of negative and positive rights. While negative reproductive rights protect individuals from state interference in their reproductive choices – ensuring access to contraception, abortion, and assisted reproductive technologies (ARTs) without restriction – positive reproductive rights imply an obligation to facilitate reproduction through subsidies, public funding, or institutional support. This paper examines whether the promotion of positive reproductive rights is compatible with the goal of fostering family diversity.

The central policy dilemma lies in the fact that any systematic public provision of reproductive services risks reinforcing a particular model of family, typically centered on biological reproduction, at the expense of alternative forms of kinship; while the lack of public provision raises a problem of distributive justice in reproductive opportunities. Indeed, if the state subsidizes ARTs only for infertile heterosexual couples, it discriminates against single individuals, same-sex couples, and other family structures, thus creating exclusionary barriers for diverse family structures. If, conversely, ARTs are subsidized universally, public policy may still reinforce biological reproduction as the normative model, and its primacy over non-biological forms of parenthood, such as adoption or multi-parent arrangements. Meanwhile, withdrawing subsidies altogether may preserve neutrality but fails to address existing inequalities in reproductive opportunities, e.g. it discriminates against individuals who cannot reproduce via sexual intercourse and/or who cannot afford access to ARTs.

Thus, there appears to be an inherent tension between the goals of (1) enhancing reproductive freedom (2) promoting family diversity, and (3) ensuring justice in the distribution of reproductive resources. No single policy option successfully fulfills all three principles without trade-offs, but each approach sacrifices at least one of the key objectives. This “tragedy of positive reproductive rights” reveals a potential tension between (positive) reproductive freedom and family diversity.

The paper concludes by engaging with Lee and Di Nucci's claim that we should depart from positive reproductive rights, but rather frame the issue as a state's imperfect duty to benefit involuntarily childless people in relation to their parental aspiration (2023). In other words, instead of direct subsidies for ARTs, a possible solution is for states to focus on fostering cultural shifts that broaden societal conceptions of family beyond biological reproduction. This approach may mitigate some of the expressive harms while avoiding direct policy contradictions. However, the question remains: when faced with mutually incompatible policy goals, which principle should take precedence?

Moral Asymmetry and Conscientious Objections: Revisiting Negative and Positive Rights in Healthcare

Tzofit Ofengenden

This talk critically examines the moral asymmetry between negative and positive conscientious objections in healthcare by exploring their ties to the distinction between negative and positive rights and duties. Traditionally, negative duties—such as refraining from harm—are viewed as more stringent than positive duties, like providing aid. Negative conscientious objections, which protect healthcare professionals (HCPs) from violating their own moral beliefs by refusing to provide certain services, are often given precedence over positive conscientious objections, where HCPs seek to provide care aligned with their conscience, even if legally or institutionally restricted.

This analysis challenges the assumed priority of negative duties and highlights that both negative and positive rights inherently require a combination of duties. Drawing on the works of Henry Shue, James Rachels, and others, this presentation demonstrates that the moral weight of duties is context-dependent. Cases where violations of positive duties are more egregious than violations of negative duties will be explored, alongside the implications for HCPs' rights and patients' rights.

Ultimately, this presentation argues for a more consistent and equitable approach to conscientious objections in healthcare. Positive conscientious appeals, often centered on patient well-being, deserve moral consideration equal to, if not greater than, negative appeals. In a pluralistic society, both types of conscientious objections should be accommodated to ensure respect for diverse moral commitments and the promotion of patient-centered care.

Artificial Intelligence in Mental Health: Navigating Ethical and Clinical Challenges in Virtual Therapy

Temiloluwa Moronfolu Oyundoyin

The increasing adoption of artificial intelligence (AI) into mental health care has transformed therapeutic practices by introducing virtual therapy solutions that enhance accessibility, affordability, and scalability. AI-driven virtual therapists and companions offer immediate support, personalized interventions, and real-time monitoring, addressing global mental health challenges such as clinician shortages and stigma-related barriers to care. However, despite its potential, AI in virtual therapy raises critical ethical and clinical challenges, particularly regarding data privacy, algorithmic bias, emotional authenticity, and professional accountability.

This paper explores the dual impact of AI in mental health its ability to augment therapeutic practices while also presenting risks to the integrity of human-centered care. One major ethical concern is privacy and data security, as AI systems rely on sensitive personal data, making them vulnerable to breaches and unauthorized access. Additionally, algorithmic bias in AI-based mental health diagnostics and interventions could exacerbate disparities, particularly among underrepresented communities. Clinically, AI lacks the nuanced empathy and contextual sensitivity that human therapists provide, raising concerns about user dependency, misdiagnosis, and the erosion of the therapeutic alliance.

From a regulatory standpoint, the absence of standardized ethical frameworks and accountability mechanisms further complicates AI's integration into mental health care. Determining liability in cases of AI-driven misdiagnosis or ineffective treatment remains a significant challenge. Ethical AI deployment requires clear guidelines, emphasizing transparency, informed consent, and human oversight to ensure that AI systems remain tools for support rather than substitutes for professional care.

To navigate these challenges, this paper advocates for a hybrid therapy model that integrates AI as a complement to human practitioners rather than as a replacement. Implementing robust ethical guidelines, continuous monitoring, and AI-human collaboration will be crucial in ensuring responsible AI deployment in mental health care. By addressing these ethical and clinical concerns, AI has the potential to revolutionize virtual therapy while safeguarding human dignity, emotional well-being, and equitable access to care.

Large Language Models (LLMs) in Medical Co-Reasoning

Johann-Christian Põder, Isa Roese, Georg Fuellen

This project investigates the ability of a custom generative AI/LLM – referred to as the MedEthicsAgent – to evaluate the ethicality of AI/LLM-based personalized biomedical intervention recommendations. Porsdam Mann et al. (2024) convincingly argue that large language models (LLMs) should be included as co-reasoners in the medical decision-making process, thereby extending the proposal of Salloch and Eriksen (2024), which highlights the role of patients as active participants in reasoning processes involving artificial intelligence.

However, in the wake of the revolutionary emergence of LLMs, their potential to function as co-reasoners – both in health-related self-management and in clinical practice – must be tested not only in terms of epistemic validity and technical robustness, but also with respect to social interaction and ethical soundness.

Our approach is grounded in the insight that a "mixture-of-agents" (MoA) framework enhances the capabilities of LLMs (Wang et al., 2024). To critically examine how LLMs perform within a multi-agent setting aimed at improving the ethical quality of medical co-reasoning involving AI, we apply the following methodology (partly building on the work of Fuellen et al. (2024):
(1) Creation of a custom LLM (ChatGPT4o) for ethics evaluation with help of well-considered a) special instructions on ethics, b) an extra knowledge base for medical-ethical information, c) web-search capability. (2) Generation of a set of LLM-based personalized biomedical intervention recommendations from the field of longevity. (3) Ethical evaluation of the LLM-based personalized biomedical intervention recommendations by "MedEthicsAgent". (4) Human-based benchmarking and analyses of "MedEthicsAgent"-evaluations by ethics

experts in collaboration with medical experts. As a last step (5) we conclude with an outlook which considers the implications and potential of the "mixture-of-agents" approach.

Our study of a medical ethics-tailored LLM aims to provide valuable insights into the ability of custom models to assess the ethical dimensions of LLM-generated biomedical recommendations. By exploring both the potential and the limitations of such systems in medical co-reasoning, this project contributes to enhancing the trustworthiness of AI in healthcare (cf. Põder and Helgesson 2025).

In our presentation, we will share experiences from this study and invite discussion on whether a custom LLM like the "MedEthicsAgent" (a customized ChatGPT) can serve as a valuable ethical co-reasoner – supporting patients (and clinicians) in better understanding the ethical aspects of LLM-generated medical advice, thereby fostering more informed and reflective decision-making.

References

Fuellen G, Kulaga A, Lobentanzer S, Unfried M, Avelar RA, Palmer D, Kennedy BK. Validation requirements for AI-based intervention-evaluation in aging and longevity research and practice. Ageing Res Rev. 2025 Feb;104:102617. https://doi.org/10.1016/j.arr.2024.102617

Põder, J.-C., Helgesson, G. (2025) Ethical aspects of generative AI in medicine, in: Hoffmann, C. H, Bansal, D. (eds), AI Ethics in Practice, Springer https://link.springer.com/book/9783031870224?srsltid=AfmBOopLvSpxcjYpkuqrqn4A0-NBi0IY5jxJbFmFfFPH1w4xhiU1fjAM

Porsdam Mann, S., Earp, B. D., Liu, P., & Savulescu, J. (2024). Reasons in the Loop: The Role of Large Language Models in Medical Co-Reasoning. The American Journal of Bioethics, 24(9), 105–107. doi.org/10.1080/15265161.2024.2383121

Salloch, S., and A. Eriksen (2024). What are humans doing in the loop? Co-reasoning and practical judgment when using machine learning-driven decision aids. The American Journal of Bioethics 24 (9):67–78. https://doi.org/10.1080/15265161.2024.2353800

Wang, J, Wang, J, Athiwaratkun, B, Zhang, C, Zou, J (2024) "Mixture-of-Agents Enhances Large Language Model Capabilities." ArXiv, 7 June 2024, https://arxiv.org/abs/2406.04692

Reproductive Ethics

James Robinson

Some of the most widely-accepted arguments in favour of abortion seem to undermine the view that infanticide is impermissible. In this paper, I outline a proposal that addresses this issue, arguing that the impermissibility of infanticide can be defended in a way that is consistent with traditional arguments in favour of abortion. I argue that killing an infant would violate its *bodily rights,* and so there are strong presumptive reasons against infanticide. I further argue that foetuses do not have bodily rights and so these same reasons cannot be used to defend the impermissibility of abortion. To support this argument, I firstly suggest some ways in which killing someone requires violating their bodily rights. I then argue that bodily rights begin at birth, and so infants have bodily rights, but foetuses do not. When taken together with the traditional arguments in favour of abortion, this proposal suggests an important result in the abortion debate: there are philosophical grounds for defending both the permissibility of abortion and the impermissibility of infanticide.

Withdrawing and Withholding Treatments: Normative and Psychological Challenges in Healthcare Priority Setting

Liam Strand

Background: When medical treatments are not deemed cost-effective, given considerations of e.g., needs and severity, and therefore denied reimbursement, the treatment is commonly withheld from all future patients. However, should the treatment also be withdrawn from patients who have gained early access to it? While normative analyses and clinical guidelines suggest yes, empirical studies and policy practices indicate otherwise.

Aim: The overall aim of the thesis was to explore ethical and psychological aspects of withdrawing treatments in relation to cost-effectiveness, given that withholding is justified. In addition, there was an ambition to formulate ethically justified reimbursement recommendations that account for psychological factors in human judgment and decision-making.

Methods: The overall methodological approach was rooted in empirical ethics. Three empirical studies and one normative study were conducted: an interview study with eight physicians and six patient organizations representatives; two online experiments (n=1067; n=1404); and a normative study based on a reflective equilibrium process.

Results: The interviews showed that in some respects, treatment withdrawal is deemed as ethically equivalent to withholding, while in other aspects, it is deemed as ethically more problematic. The experiments showed that when presented with a detailed vignette of the rationing situation, people express withdrawing to be less acceptable than withholding. However, when presented with short and concise statements, no general difference is perceived. Moreover, withdrawing is deemed more acceptable at the bedside level than at the policy level. However, different circumstances can render withholding equally, and sometimes even more, unacceptable than withdrawing. The normative analysis shows support for an approach to withdrawing and withholding treatments where: If withholding is acceptable, then withdrawing is too; early access to treatments that are yet to be assessed for cost-effectiveness is in principle problematic; but if early access is to be given, physicians must inform patients that the treatment will be withdrawn if it does not get reimbursed.

Conclusions: The thesis demonstrates the potential normative value of empirical research within a reflective equilibrium process by using insights from interviews and experiments when formulating a balanced and justified approach to withdrawing and withholding treatments in healthcare priority setting.

Ethical Requirements for Research with Human Participants in Precision Medicine

Karolina Strzebońska

Medical ethics has undergone some paradigm shifts starting from traditional paternalism through the ethics of patients' autonomy and informed consent to a novel emerging concept of precision or personalized medicine [1].

Precision medicine concerns a new approach in treating patients by tailoring the appropriate therapy to the individual needs and genetic characteristics of a single patient. To test new potential therapeutics faster and more efficiently, new models of conducting clinical trials have emerged. They are called "*basket*" and "*umbrella*" clinical trial designs, and the number of such trials is rapidly increasing [2]. Still, there is a lack of descriptive and normative ethical analyses of basket and umbrella trials.

Ezekiel J. Emanuel, David Wendler, and Christine Grady formulated seven requirements for the ethical conduct of clinical research, which provide a systematic and coherent framework of the ethical principles established in many guidelines for conducting research involving human participants. These seven requirements are: 1. social or scientific value, 2. scientific validity, 3. fair subject selection, 4. favorable risk-benefit ratio, 5. independent review, 6. informed consent and 7. respect for potential and enrolled subjects [3].

Novel clinical trial designs in precision medicine may pose challenges regarding these seven fundamental ethical requirements for clinical research, which need a careful bioethical analysis.

In my presentation I will focus on the novel clinical trial designs in precision medicine and analyse their characteristics in relation to ethical principles. My main hypothesis is that all seven ethical requirements are challenged in precision medicine research.

First, I will provide the short description on novel clinical trials designs and present major differences to standard designs. Second, I will outline the seven basic requirements of ethical clinical research. Third, I will give examples to each requirement that may be challenged in precision medicine clinical trials.

Careful analysis of ethical standards in novel research models in the era of precision medicine will trigger a debate on the ethical aspects of the research in precision medicine and may enable the proposal of recommendations to restrain or eliminate ethical concerns.

References

1. Gefanas E, Cekanauskaite, Tuzaite E, Drainseika V, Characiejus D. Does the „new philosophy" in predicitive, preventive and personalized medicine require new ethics? EPMA Journal. 2011; 2:141-147. doi:10.1007/s13167-011-0078-x.
2. Strzebonska K, Waligora M. Umbrella and basket trials in oncology: ethical challenges. BMC Med Ethics. 2019; 20:1-10. doi:https://doi.org/10.1186/s12910-019-0395-5.
3. Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? JAMA. 2000; 283: 2701-11. doi:10.1001/jama.283.20.2701.

From Transparency to Stakeholder Participation: What AI Paternalism Teaches us About Autonomy Threats

Ellen Svensson

AI is entering the healthcare sector in a big way, being used in everything from diagnostics to radiology and treatment suggestions. In this transition, several concerns have been raised regarding black box and opacity issues, as calls to explainable AI and increased transparency have become frequent. In this paper, I shall argue that to ensure a safe and responsible transition towards healthcare systems that integrate AI, the focus ought to be shifted from

calls to transparency to a larger focus on stakeholder participation in medical decision-making. This I claim since concerns are being raised about the risk of AI paternalism. (Diaz Milian & Bhattacharyya, 2023; Ferrario et al., 2023; Kühler, 2022; Lorenzini et al., 2023; Luxton, 2022; Muralidharan et al., 2024; Savulescu et al., 2024; Segers, 2023; Voinea et al., 2024). However, there is good reason to argue that paternalism has nothing to do with AI. Paternalism seems to be something that only humans are capable of since it, at the very least, would require some kind of agency or intention on the part of AI. As current definitions of AI paternalism have been presented, they either track the idea that paternalism is a kind of interference motivated by beneficence (Dworkin, 1988; Grill, 2007) or the idea that paternalism is an insulting attitude motivated by a negative evaluation of the paternalized (Quong, 2010; Shiffrin, 2000; Tsai, 2014). As we stand today, the AI systems we use do not possess these fundamental human capabilities, and therefore, a concept like paternalism could not make sense concerning AI without the author being required to do some excessive anthropomorphization of these systems. However, in healthcare, paternalism has historically been practiced by patients not participating enough in medical decision-making and by letting beneficence outrank autonomy. The paternalistic paradigm in healthcare can be summarized under the slogan "doctor knows best". Today, when more and more healthcare decisions are being outsourced to AI systems, it seems we are moving into a new paradigm of healthcare where "AI knows best". I, therefore, argue that there is good reason to think that paternalism may be the correct diagnosis for some of the ethical concerns raised by the integration of AI in medical decision-making. Most strikingly, the threat that AI poses to human autonomy. If this assumption is correct, and paternalism is the correct diagnosis for the problem, then paternalism may also be able to provide us with a cure for these autonomy threats. That is, by highlighting that to avoid violations of human autonomy, stakeholders must be given legitimate input in the decision-making process. In this paper, I argue that if paternalism can provide the correct diagnosis and cure to AI autonomy threats, then the focus ought to be shifted from black-box and opacity concerns regarding AI-integrated decision-making and be moved to an increased focus on patient participation in the decision-making process.

Panel Discussion on the Ethical Implications of Current and Future Prenatal Genetic Testing

The Swedish National Council on Medical Ethics

The Swedish National Council on Medical Ethics (Smer) is currently working on a project on genetic analyses and whole genome sequencing in healthcare. One of the topics we are analysing is genetic testing in reproductive decisions. Refined analytical methods and increased knowledge mean increased opportunities to use genetic analyses in the context of reproduction and pregnancy. Prenatal genetic testing can be used both when there is an increased suspicion of disease (e.g. for individuals with a family history of genetic disease) or, in the form of screening, when there is no such suspicion.

While publicly funded healthcare in Sweden normally offer tests for trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome), trisomy 13 (Patau syndrome) and sex chromosome abnormalities, including Turner syndrome and Klinefelter syndrome, private companies also market extended tests for more than 92 different chromosomal

abnormalities. In some regions, whole exome or whole genome sequencing is offered to explain an already detected ultrasound finding or abnormality. In the future one can imagine a situation where private companies will offer WES/WGS to all future parents.

In this panel discussion we would like to address the different ethical dilemmas in relation to this development, such as: Should we as a society welcome or discourage this development? Which conditions should be included in the offer from the public health care system? How should information about tests and results be communicated? How can future parents handle the information and make reproductive choices? Does increased use of genetic testing in the context of reproduction lead to stigmatisation and discrimination on genetic grounds? Does it threaten human value and equality?

Moderator/chair:

Michael Lövtrup, Research officer, The Swedish National Council of Medical Ethics

Speakers:

Niklas Juth, professor of Medical Ethics, Uppsala university, expert member of The Swedish National Council of Medical Ethics

Charlotta Ingvoldstad Malmgren, Genetic counsellor, member of the Swedish network for information about prenatal diagnostics

Emelie Mynde, lawyer, The Swedish National Association for People with Intellectual Disability (FUB).