Karolinska Institutet

KIMEC 2023 Abstracts

1. Joar Björk, Karolinska Institutet. From bad to worse – on the ethical permissibility of different forms of consentless care

As per Swedish healthcare law, patients' consent is necessary for healthcare interventions except in specified situations (e.g. coercive psychiatric care, care for some contagious diseases and substance abuse). Despite this, patients with cognitive impairments are routinely subject to somatic care interventions in nursing homes, primary health care, and during hospitalizations. In some situations the patients, despite not having given consent, willingly go along with the care provided. In other situations patients protest which may make healthcare personnel use strategies like cajoling, diverting, fooling or forcing the patients in order to provide the intervention. There is currently no unified taxonomy to describe such coercion-like strategies used by healthcare personnel outside of legally mandated coercive care. This project aims to provide a taxonomy and a principled ethical assessment of different forms of consentless care, which could assist healthcare personnel to avoid the worst ethical pitfalls when navigating this tricky ethical territory.

Joar Björk is a specialist physician working in palliative healthcare and as a clinical ethical consultant. His PhD was on issues of patient responsibility in healthcare priority setting. His current research interests include coercion, authenticity and priority setting, and he holds a research position at Uppsala University.

2. Isra Black, University College London & Lisa Forsberg, University of Oxford. Is consent a necessary condition for the lawfulness of medical interventions?

We challenge the common assumption that patient consent is a necessary condition for the lawfulness of medical interventions provided to autonomous individuals.

'Valid consent'—given by a patient who is adequately informed, who has decision-making capacity, and whose decision is not subject to voluntariness-undermining external influence—is often claimed to be a necessary condition for the permissibility of medical treatment.

However, legal protection against treatment without consent fails to cover the full range of interventions that may be administered to autonomous patients. We show that, in English law:

1) it is not *unlawful* for the purposes of the tort of battery for a professional (*D*) to administer a treatment (T) to a patient (*P*), notwithstanding the absence of valid consent, when T meets certain criteria (*viz*, absence of physical interference)

2) for Ts provided without valid consent outside the scope of battery, there exists a subset of Ts for which the tort of negligence fails to provide a remedy (*viz*, when impermissible interference with personal autonomy is not actionable damage)

3) for Ts covered neither by battery, nor negligence, the criminal law offers incomplete protection

To wit, valid consent is not a necessary condition for the lawfulness of medical interventions.

Isra Black is a Lecturer in Health Law at UCL Faculty of Laws and an Associate Member of the Rotman Institute of Philosophy. His area of research specialisation lies in the law and philosophy of medical treatment and the theorisation of health law.

Lisa Forsberg is a Research Fellow in the Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, University of Oxford, a Fulford Junior Research Fellow at Somerville College, Oxford, and an Associate of the Rotman Institute of Philosophy and the Legal Priorities Project. Lisa specialises in moral and legal philosophy, especially normative and practical ethics and the philosophy of medical and criminal law.

3. Helene Bodegård, Karolinska Institutet. Patientcentred or personcentred – what's the difference?

Many countries and health care organisations has chosen either *Patient-centredness* or *Person-centredness* as an approach to ensure that the patient's values and preferences are considered in the health care meetings. The concepts evolved as a counter force and alternative to the paternalism and narrow Biographymedical focus that permeated health care and often reduced the patient to the role of a passive receiver of medical interventions. The concepts both lack a unified definition but has often been defined by what they are not: disease-centred, hospital-centred or doctor-centred. A few key aspects are present in both concepts and can be found in the different methodologies, such

as giving room for the patient's narrative, having a holistic approach where the patient is seen as a whole actual person and, exploring the patient's preferences in order to engage the patient and health care provider in shared decision-making.

Having a patient- or person-centred approach has in studies been connected to outcome such as increased recovery and mental health, increased adherence to treatment and a reduction of unnecessary prescriptions and referrals, to mentions a few. It is also common that papers on person-centred care refers to research made under the patient-centred flag to back up claims about its effects and vice versa.

Clearly, the two concepts resemble, so what are the actual differences?

This presentation will aim at giving a brief history of the emergence of the two concepts, an insight into the criticism from the proponents of one of the concepts towards the other and, shed some light on widespread misapprehensions and actual differences between the concepts.

Helene Bodegård is a specialist in general medicine at Gustavsbergs Primary Care Centre in Värmdö outside of Stockholm. She is a lecturer in patient-centred consultation methodology for medical students, doctors in specialist training and their supervisors, mainly general practioners. Since 2015 she is performing research at the Centre for Healthcare Ethics at Karolinska Institutet. Her research is part of a programme in Person-centred Care, a collaboration between researchers in medical ethics at Karolinska Institutet, KTH Royal Institute of Technology and the Universities of Stockholm, Göteborg and Linköping. In her research she explores factors that affects doctor's propensity to interact with their patients in a patient-centred manner and she takes a particular interest in Shared Decision Making. The research is part of her doctoral project.

4. Greg Bognar, Stockholm University. Trading Off Lives and Livelihoods.

Public health emergencies sometimes require the restriction of civil liberties through social distancing: lockdowns, quarantines, the closure of public spaces or institutions, and so on. Social distancing measures can decrease mortality and morbidity, but they also cause social and economic harm. Policy makers have to make trade-offs between ``lives and livelihoods," while introducing only the

minimally necessary restrictions on civil liberties. Traditionally, cost-benefit analysis has played a central role in formulating these trade-offs.

Recently, however, some philosophers have argued that the trade-offs should be made on the basis of contractualist moral theory instead. In this paper, I argue against the use of contractualism for this purpose.

Greg Bognar is Associate Professor in Practical Philosophy at Stockholm University and a Senior Researcher at the Stockholm Centre for Healthcare Ethics (CHE). His research is in normative and applied ethics, especially Biographyethics and PPE (politics, philosophy, and economics). He is co-author of the book The Ethics of Health Care Rationing: An Introduction (Routledge, 2014; Second, expanded edition 2022) and co-editor of Ageing without Ageism: Conceptual Puzzles and Policy Proposals (Oxford University Press, 2023).

5. Linus Broström, Lund University. Research subjects, bystanders, and research protectees.

The protection of research subjects has long been recognized as imperative, and is central in many ethics guidelines and regulations. But who counts as a research subject? And who *should* count as one, given the important normative role this concept plays in research ethics governance? In this presentation we argue that common (narrow) understandings of the notion of a research subject are unacceptable, and that the concept should be replaced with the broader notion of a *research protectee*, focusing not on who the research is "about" but on who might be negatively affected by it. We end with addressing a couple of worries.

Linus Broström is a lecturer in medical ethics at the Department of Clinical Sciences, Lund, Lund University.

6. Mónica Cano Abadía, BBMRI-ERIC. Trustworthiness in Medical Artificial Intelligence.

Developments in Artificial Intelligence (AI) are progressing rapidly in the medical field and is expected to have a practical impact on clinicians, health systems and patients (Topol, 2019). Against this background of expectations, researchers and practitioners are carefully studying the ethical and societal implications of AI use in medicine to avoid harmful consequences for individuals and groups, especially for the most vulnerable populations. From epistemic concerns to normative

issues, scholars observe a key concern to be the loss of trust in the case of medical use of AI-based technologies that are not yet ready. Trust is a key requirement for the ethical use of AI. As such, it has been chosen as one of the guiding principles by the High-Level Expert Group on AI of the European Commission and identified as the defining paradigm for their ethics guidelines. This paper aims at presenting the current discourses on trustworthiness in the field of ethics of AI, especially focusing on the normative frameworks that propose trustworthiness as a key principle for the ethical use of AI. Additionally, it will link the current literature on trustworthy AI it to broader conversations of the role of trust in medical ethics and philosophical perspectives on trust in medicine.

Mónica Cano Abadía is Senior Scientist, Deputy Head of the ELSI Services and Research Unit, and the Gender, Equality, and Diversity Specialist at BBMRI-ERIC. She has been a postdoctoral researcher at the Center for Advanced Studies – South East Europe (University of Rijeka). She has been a part of the research project "Justice, Citizenship and Vulnerability: Precarious Narratives and Intersectional Approaches" from the University of La Laguna (2016-2019). She has been a postdoctoral University Assistant at the Section of Political Philosophy (Institute of Philosophy, University of Graz). She currently teaches at the master's programme Interdisciplinary Women's and Gender Studies (University of Graz) and at the Master's Degree in Interdisciplinary Gender Studies (Autonomous University of Madrid). Currently, at BBMRI-ERIC, her research focus in several projects is the analysis of ethical and societal aspects of AI with an emphasis on issues related to sex and gender.

7. Daniela Cutas, Lund University. Bodily integrity versus family interests.

In this talk, I look at tensions that may arise between respecting individuals' bodily integrity and respecting familial requests. I start by briefly reviewing three different kinds of cases: reproduction with a dying/deceased spouse, parents harvesting or using in reproduction their own offspring's reproductive material, and uterus transplants from mother to daughter. I 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 interventions are justified.

Daniela Cutas is Associate Professor of Medical Ethics at Lund University. She is a co-editor of the volumes 'Families – Beyond the Nuclear Ideal' (2012) and 'Parental Responsibility in the Context of Neuroscience and Genetics' (2017). She is particularly interested in the ethics of the legal regulation of human reproduction and parenthood.

8. Katarina Cvek, Swedish University of Agricultural Sciences. Laboratory animals – how much is a good life worth?

The principle of the 3Rs (replace, reduce and refine the use of animals) is implemented into the legislation on the use of animals for scientific purposes. To refine the situation for laboratory animals is thus a legal requirement and all animals covered by this legislation are recognised as individuals with feelings and needs and have an intrinsic value that must be respected.
Scientific knowledge is increasing regarding factors that influence animal welfare. Therefore, taken the legal demands into account and combine them with the latest scientific developments, it is an obvious obligation for the research community to continuously improve the welfare of the laboratory animals. However, economic reality and work culture are in many cases accepted as valid reasons to limit the efforts to improve the animal welfare. The ethical dilemma of the benefits of scientific advances reached from animal studies vs our responsibilities towards the animals used will be discussed.

Katarina Cvek, MSc PhD. Coordinator for laboratory animal science at SLU
I have been working with matters concerning laboratory animals at the Swedish University of Agricultural Sciences since 1999. In my work, I am responsible for the compliance to regulations as well as organising courses in laboratory animal science. I also represent the university for all matters concerning the use of animals for scientific purposes. During the last 20 years, I have had many external assignements, i.e. member of the Swedish national committee for the protection of animals used for scientific purposes and the animal ethics committee.

9. Adam Ehlert, Uppsala University. Double Threshold Prioritarianism: Some Problems and Solutions.

Prioriarianism is a distributive principle in health care priority setting. However, prioritarianism encounters an aggregation problem, since it allows for unlimited interpersonal aggregation. One way of tempering this problem with prioritarianism is to combine it with elements of sufficientarianism. An attempt at this has recently been done by Gustavsson & Juth. They propose a theory called Double Threshold Prioritarianism (DTP), which combines a prioritarian axiology with two thresholds. DTP is a promising sketch of a distributive principle, but this theory is new and requires further elaboration to be a viable contender. I will raise three problems for DTP, and defend the theory against these problems. Some of these criticisms are novel, while some have been raised before. If we can, as I will argue, defend DTP against these problems, that would be a point in favor of the theory.

Adam Ehlert is a PhD student in clinical medical ethics at the Centre for Research Ethics and Biographyethics at Uppsala university. He is working in the research project Just Severity, studying the philosophical background of severity as a priority setting criterion in health care. Ehlert has a BA and MA in practical philosophy, both from Uppsala university.

10. Ryan Essex, University of Greenwich. Strike action in healthcare settings.

Strike action is a remarkably common phenomenon in healthcare, from health workers withdrawing their labour in protest of the 2021 coup in Myanmar to those in the UK demanding greater investment in the workforce and healthcare system. Regardless its context however, strike action often prompts passionate and polarising debate, raising a series of distinct issues related to the delivery of care and patient wellbeing. This presentation will draw on recent work that has synthesised the empirical literature related to strike action, exploring patient outcomes and healthcare delivery. It will also critique the most prominent arguments for and against strike action found in the Biographyethics literature and made by governments and health authorities. Building on this work a deliberative framework will be proposed The framework outlines two broad conditions that should be met if strike action is to be justified, whether 1) it makes demands or raises grievances about some form of injustice, unfairness or threat to health and when 2) the risks in striking are proportionate to its demands or grievances. It then goes on to outline two deliberative, interrelated questions that should be used to assess whether strike action meets these conditions,

namely related to the 3) social and political context of the strike and 4) the characteristics of the strike itself.

Ryan Essex is a Research Fellow at the Institute for Lifecourse Development, the University of Greenwich. He is interested in resistance/activism and their intersections with health.

11. Lisa Forsberg, University of Oxford. Is consent to psychological interventions less important than consent to bodily interventions?

It is standardly accepted that medical interventions can be permissibly administered to a patient who has decision-making capacity only when she has given her valid consent to the intervention. But the requirement for valid medical consent is almost always discussed in relation to interventions that physically interfere with our bodies, such as touching and the incision or insertion of instruments into the body ('bodily interventions' or 'BIs'). There has been very little discussion in the literature regarding whether or when a consent requirement obtains also in respect of interventions that interfere with the patient via psychological processes, such as psychotherapy and counselling (henceforth 'psychological interventions' or 'PIs'). Moreover, conventional consent requirements in respect of PIs are laxer than the analogous requirements in respect of BIs. One possible explanation for this is that many endorse the Differential Importance View—the view that it is presumptively morally less important to obtain explicit valid consent for PIs than for BIs. In this article we argue against the Differential Importance View, by considering and rejecting three possible justifications one might offer in support of it, based on harm, implicit consent, and wronging.

Lisa Forsberg is a Research Fellow in the Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, University of Oxford, and a Fulford Junior Research Fellow at Somerville College, Oxford. Prior to this, she was a British Academy Postdoctoral Fellow in the Faculty of Law, University of Oxford, leading a project on medical consent. She is also a research affiliate with the Legal Priorities Project and the Rotman Institute of Philosophy. Lisa specialises in moral and legal philosophy, especially normative and practical ethics and the philosophy of medical and criminal law.

12. Melanie Goisauf & Michaela Th. Mayrhofer, BBMRI-ERIC. Ethical challenges of responsible data sharing and reuse practices.

Large amounts of health data generated in research and healthcare contexts are invaluable sources of knowledge for the advance of Biographymedical research. Investments have been made to build (federated) data infrastructures to facilitate data sharing for research across international borders. The sharing and further use of - especially genomic - data and their utilization in multiple research projects, including the development of new technologies such as medical artificial intelligence (AI), has raised a number of ethical questions regarding responsible and FAIR(ER) reuse of data, informed consent, and how to avoid potential harmful consequences for individuals and groups, e.g., regarding the sensitivity of genomic data sourced from vulnerable and ethnic groups, genetic discrimination, racial and gender bias and potential re-identifiability of research participants. In building on findings of several research projects around (genomic) data sharing (CINECA) and the development of new technologies in Biographymedical research and medicine (EuCanImage), our presentation highlights key ethical challenges and how to overcome them in current data sharing and reuse practices.

Melanie Goisauf is Senior Scientist at the European Research Infrastructure BBMRI-ERIC. She has a background in sociology (doctorate with honours), with a focus on science and technology studies (STS), gender studies and qualitative research methods. Her dissertation was awarded the prize for best thesis in 2017 by the research network "Gender and Agency" of the University of Vienna. She is visiting researcher at Newcastle University, and she has worked as lecturer at the University of Vienna and Malta. Her current research focus in the field of Biographymedical research is on the ethical and societal implications of health data sharing and medical artificial intelligence. She is leading the "Ethics of AI Lab" within BBMRI-ERIC. She is ethics advisor and member of the ethics and legal advisory board in large European projects.

Michaela Th. Mayrhofer is a social scientist with a PhD (cotutelle) from the Ecole des Hautes Etudes en Sciences Sociales and the University of Vienna respectively. Her academic career led her to France, Belgium, the UK, Switzerland and Austria. Recent research Fellowships comprise the Alpen-Adria-Universität Klagenfurt and the University of Newcastle. Since 2019, she is department Head of ELSI Services & Research at BBMRI-ERIC, the research infrastructure for Biographybanks and Biographymolecular resources. From February to August 2020, she served as Interim Co-Director General of BBMRI-ERIC. Since 2023, she joined the review board of Frontiers in Genetics as review editor. She also serves

in several (S)EABs. Trained in qualitative methodology and science and technology studies, her current research focus lies on the governance of the life sciences and the ethics of AI.

13. Erik Gustavsson, Linköping University. Children and healthcare priority setting.

Should children be given priority in healthcare priority setting? Several studies suggest that there are widespread moral intuitions that they should. While the literature offers several justifications for *why* children should have such priority, these accounts tend to have a similar assumption in place: the relevant idea about well-being is the same across all life spans. However, there is a growing body of literature suggesting that there is something special about children's well-being compared to adults. These accounts tend to share a common feature: children's well-being comprises an objective component, that can be motivated in various ways. For example, children's motivations are often not compatible with their best interests, children's point of view seems too immature to furnish attitudes robust enough for a subjective theory about well-being, and children are not yet fully formed agents. Items that often go on the standard objective list theory are, for example, freedom and knowledge, whereas such accounts for children tend to list different items such as unstructured imaginative play and sexual innocence. The talk explores the relevance of the recent theoretical discussion about children's well-being for priority setting, more specifically, it discusses its relevance for justifying why children should be given priority.

Erik Gustavsson is a senior lecturer in applied ethics with a special focus on medical ethics at Linköping University in Sweden. He completed his doctoral thesis on needs in healthcare priority setting in 2018. Since then, his main research interest relates to medical ethics, especially ethical issues that arise in healthcare priority setting. During 2023 he primarily works on priority setting in crisis and war as well as questions about severity of disease.

14. Thomas Hartvigsson, University of Gothenburg. The goals of forensic psychiatric treatment and research.

Forensic psychiatric care is an area of medical expertise concerned with the care and treatment of people who have committed crimes under the influence of mental disorder. In addition to the traditional goals of health care and psychiatry, forensic psychiatry also has a clearly articulated goal of public protection.

In this talk we aim to explore the tensions and dilemmas that arise from within and between these goals and explore the implications for care, treatment and research. The goals inform and underlie standards of what counts as a successful treatment. If the goal is unclear, then this will be mirrored by unclear standards of success. The dual goals of forensic psychiatry contributes to such a confusion. When these goals pull in different directions, they must be weighed against each other, and some goal prioritised over the other. This requires that the differences and tensions between the goals are clearly articulated. By more clearly articulating the contents of these goals and exploring their interrelations we aim to provide a guide to clearly articulating the goal of treatment in care and research as well a roadmap to trade offs that needs to be made.

Thomas Hartvigsson is a researcher in practical philosophy at the University of Gothenburg. His research is primarily concerned with the intersection of law, ethics and mental health. He is affiliated with CELAM – Centre for Ethics, Law and Mental Health - and the Essex Autonomy Project.

15. Sarah de Heer, Lund University. ADM systems in healthcare and the IVDR – transparency despair or transparency.

The In Vitro Diagnostics Regulation (**IVDR**) governs a particular form of AI in health care, namely ADM systems used in personalised medicine, since such systems examines human bodily samples to, for instance, suggest a treatment. Thus, ADM systems are an '*in vitro* diagnostic medical device' (Article 2(2) IVDR).

One of the IVDR's aims is safeguarding transparency, which is a multifaceted concept that includes access to relevant and concise information in an intelligible manner. However, since ADM systems are built with machine learning techniques, they contain AI's so-called 'black box'. Understanding their *modus operandi* may be cumbersome – or even impossible, which means that these systems may be incomprehensible and, consequently, curb transparency.

The question is whether transparency should not be reconsidered by moving away from a strict dichotomy. Accordingly, this contribution argues for a holistic approach that contextualise ADM systems, which includes considering medical ethics. Further, transparency should not only be assessed by focussing on the outcome phase but also by elaborating on how transparency can be achieved during the input phase. The contribution uses the doctrinal method and scrutinizes legislation, case law, and literature.

Sarah de Heer is a doctoral candidate at the Faculty of Law of Lund University. Her PhD project is part of the AICARE project and focuses on the right to good administration and AI systems in personalised medicine.

16. Kristina Hug, Lund University. To tell or not to tell – That is not the question. Normative implications of detecting Alzheimer's before the onset of symptoms.

Alzheimer's disease (AD) makes 60–70% of all dementia cases, is a major cause of disability, dependency and mortality, especially in older population, and has serious psychological and physical effects on AD patients and their families. With the help of Biographymarkers, new ways to accurately detect AD at an early stage have been found, able to reveal the AD status decades before the onset of clinical symptoms. Early accurate detection of AD opens new possibilities, but raises ethical questions. Medication for retarding the onset of AD is under way, and advantages of getting an accurate prognosis of AD are many, e.g. starting treatment or accessing assistance earlier. But knowing one's AD status years before any clinical symptoms appear can also have disadvantages, e.g. affect persons' relationship with their families, stigmatize them or cause hypervigilance for symptoms. This presentation analyses the ethical challenges raised by early detection of AD, and discusses the normative implications of getting a diagnosis years before the onset of symptoms. How should the interests of persons with early detected AD be balanced against the interests of other stakeholders? How can the prognostic information be best disclosed to patients, and when?

Researcher in Medical Ethics, Department of Clinical Sciences Lund, Lund University, with 20 years' teaching experience in different settings, including Karolinska Institute (since 2009), Lithuanian University of Health Sciences (2003-2006), Advanced Certificate Program in Research Ethics at Vilnius University and the Albany Medical College and the Graduate College of Union University (2005-2012). Her dissertation ("Building the Bridge from Bench to Bedside: Ethical Issues in Translational Stem Cell Research", Lund University, 2012) analyzed ethical questions arising at different levels of translation of knowledge generated by stem cell research, which is a lasting research interest. Coeditor/coauthor of the book "Translational Stem Cell Research. Issues Beyond the Debate on the Moral Status of the Human Embryo", Springer, 2011, and editorial board member for "Stem Cell Reviews and Reports" (2009-2014).

17. Niklas Juth, Uppsala University. Severity and prioritarianism: a suitable couple.

This presentation discusses what is the most plausible moral basis for severity as a priority setting criterion in health care: prioritarianism or egalitarianism. Although both notions of justice have initial appeal, egalitarianism as a basis of severity has several problems that prioritarianism lack. Among those are the problem of admitting partial defeat, since also egalitarianism arguably needs a non-equality-based reference level in order to determine the magnitude of severity. Moreover, according to egalitarianism, how severe one person's illness unreasonably varies with the severity of other persons. Furthermore, egalitarianism has yet to explain what potential aspects of inequality matters and why in relation to severity of illness. In the end, if equality of health matters, it arguably is not because it has anything to do with severity.

Niklas Juth is full Professor of Medical Ethics. The chair has a clinical focus and is funded jointly by Uppsala University and the region. His research is focused on the ethical dilemmas that arise in the intersection of political philosophy and medical ethics, in particular questions concerning autonomy and justice in health care. In recent years, his research has been focused on compulsory care in both psychiatric and somatic settings. He has also worked with priorities in relation to orphan drugs, and issues relating to end-of-life care and screening.

18. Elin Lampa, Uppsala Universitet. Public involvement in research with forced migrants - exploring ethical issues.

Patient and public involvement (PPI) refers to an active partnership between researchers and patients or representatives of the public, where public representatives contribute to research as advisors or co-researchers. One argument for PPI is that lived experience is valuable expertise, comparable – but not identical – to researchers' knowledge; PPI has been shown to improve research quality, relevance and impact. A second, rights-based, argument states that the public have a right to be involved in research concerning them and their experiences.

However, this relies on PPI being conducted in a meaningful and inclusive way, especially when involving disadvantaged populations. In our PPI evaluations and practical experiences of PPI, we have identified a number of ethical issues specific to PPI with forced migrants.

In this project, we aim to identify ethical issues in PPI with forced migrants, through analysis of behavioural observations of research meetings, survey data, focus group interviews, and field notes, from several research projects. The analysis is ongoing, but preliminary findings include ethical issues in decision-making and responsibility, role-definition, communication around research, as well as risk for harm vs. the right to be involved. Our longer-term aim is contributing with support on ethical decision-making for teams involving forced migrant representatives.

Elin Lampa is a PhD student in public health. She has a background in nursing and global health, and has worked with health care for migrants. Her research interest is patient and public involvement in research, with a focus how researchers can involve representatives from seldom-heard groups as partners in research projects. In her PhD project, she investigates involvement with migrants, from three perspectives: assessment of the involvement; the involved contributors' own experiences, and; ethical perspectives on involvement with migrant contributors.

19. Lars Lindblom & Erik Gustavsson, Linköping University. Reasons, Public Values, and Priority Setting.

Empirical studies of publics values provide input to health care priority setting. These results are often taken to provide reasons for particular policies with regards to priorities. This presentation will explore the use of such empirical studies in the practice of priority setting from the perspective of the theory of reasons put forward by philosophers such as Parfit, Scanlon and Larmore. In general, a reason consists in a relationship between an empirical phenomenon in the world and the interests of an agent. Such interests can be studied empirically, as can the relationships between these two relata. There are, hence, three kinds of facts that needs to be captured if empirical studies of public values are to identify reasons for priority setting, and, conversely, three ways in which such studies may fail to identify information relevant to reasons. Using this framework for thinking about reasons may be helpful in indicating what empirical research that could uncover further relevant reasons for a given distribution in priority setting. This presentation will outline this approach to reasons, empirical studies of publics values and priority setting, and bring it to bear on examples from some of the priority setting processes during the recent covid pandemic.

Lars Lindblom is senior associate professor and director of the Centre for Applied Ethics at Linköping University, Sweden. He has written on assortment of

topics in applied ethics and political philosophy, including risk management, education, equality, priority setting and workplace justice.

Erik Gustavsson is a senior lecturer in applied ethics with a special focus on medical ethics at Linköping University in Sweden. He completed his doctoral thesis on needs in healthcare priority setting in 2018. Since then, his main research interest relates to medical ethics, especially ethical issues that arise in healthcare priority setting. During 2023 he primarily works on priority setting in crisis and war as well as questions about severity of disease.

20. Antoinette Lundahl, Karolinska Institutet. When is compulsory care ethically justified for patients with borderline personality disorder?

Patients with borderline personality disorder (BPD) suffer from increased emotional reactivity and sensitivity to rejection and other adverse life situations. This is expressed as emotional instability and recurrent crises with suicidal behaviour. [1,2] BPD patients are often subjected to hospital and compulsory care due to their suicidality but the collected experience indicates no or negative effects of such care, including an increase in suicidal behaviour [3-6]. In this normative study, we address common arguments in favour of compulsory care of BPD patients: (1) the patients lack decision competence, (2) the patients lack authenticity, (3) compulsory care saves the patient from suicide, (4) compulsory care is a practical solution in emergencies, (5) compulsory care safeguards against litigation, complaints, or doctor's anxiety, (6) it is better for the caregiver to "err on the safe side". We discuss these and other possible arguments for and against compulsory care of BPD patients.

Antoinette Lundahl is a doctoral student at LIME, Karolinska Institutet, Stockholm. Supervisors are professors Niklas Juth, Uppsala University and Gert Helgesson, Karolinska Institutet. She is also a consultant psychiatrist and medical director of a psychiatric hospital ward 16pecializing in personality- and anxiety disorders at S:t Göran's hospital in Stockholm.

21. Phil Marsden, Great Ormond Street Hospital for Children, London & Ayesha Ahmad, St George's University of London. "He must not know what I think": the impact of domestic abuse, coercion, and silencing on clinical decision-making in a Paediatric ITU setting.

We explore the decision-making process for a baby born with a complex underlying condition and poor, though uncertain, prognosis with fundamentally divergent treatment options - palliation and long-term home ventilation - and in the context of an abusive parental relationship. Clinicians believed both options to be ethically and clinically equally appropriate and did not offer a specific recommendation, proposing that the parent's should have the final say. The father spoke for both of them, asserting their wish to proceed with all life-sustaining treatment, including long-term ventilation. We focus on the ability of the clinical culture to respond effectively to a caregiver's discreet disclosures of domestic abuse to health professionals and the subsequent retraction of these disclosures. They were expressed with a caveat – that professional opinion is re-positioned to secure an agreement from the father that aligns with mother's view that the palliative option is in the best interests of their child. The mother declined to allow her own opinion to be made overt during the clinical consultations, telling staff that he mustn't be told what she thinks, but without explicitly expressing concerns for her safety. We consider the positional neutrality of the clinicians, and reflect on possible responses to silence(d) disclosures of domestic abuse which ultimately impact on the best interests of a child during clinical decision-making?

A qualified Social Worker with a background in community child protection and Court social work, **Phil Marsden** have worked at Great Ormond Street Hospital (GOSH) for 15 years with a particular focus on child protection and family work in the ITU and in clinical areas such as Chronic Pain where concerns around 'Perplexing Presentation' and 'Fabricated & Induced Illness' are present. I provide safeguarding supervision and training to clinical, nursing and allied health professionals across all clinical areas. I am a member of the GOSH Paediatric Ethics Service, working primarily in the area of clinical review and with a specific interest in developing the psychosocial contribution to paediatric bioethics.

Ayesha Ahmad, St George's University of London, Reader in Global Health Humanities.

22. Michaela Th. Mayrhofer, BBMRI-ERIC & Melanie Goisauf, BBMRI-ERIC. Does the Dream of Open Science Depict Ethical Considerations as a Nightmare?

Previous research has shown that data and samples are neither neutral nor separate entities, but are carrying specific cultural, political, and societal meanings and expectations. While the implementation of FAIR is more on the technical side, the datafication of health research puts it in the context of legal and ethical

requirements, expectations of research participants (data subject) as well as data providers and users. In short, it requires to address the wider societal implications and ask: How fair is FAIR? This presentation assesses the social aspects or 'ethics work' that are an integral part of data flows, especially in relation to open science and accessibility by presenting findings from common infrastructures for national cohorts in Europe.

Michaela Th. Mayrhofer is a social scientist with a PhD (cotutelle) from the Ecole des Hautes Etudes en Sciences Sociales and the University of Vienna respectively. Her academic career led her to France, Belgium, the UK, Switzerland, and Austria. Recent research Fellowships comprise the Alpen-Adria-Universität Klagenfurt and the University of Newcastle. Since 2019, she is department Head of ELSI Services & Research at BBMRI-ERIC, the research infrastructure for Biographybanks and Biographymolecular resources. That leads several WPS in projects such as CINECA, Healthy Cloud or EOSC-Life. From February to August 2020, she served as Interim Co-Director General of BBMRI-ERIC. Since 2023, she joined the review board of Frontiers in Genetics as review editor. She also serves in several (S)EABs. Trained in qualitative methodology and science and technology studies, her current research focus lies on the datafication of the life sciences.

Melanie Goisauf is Senior Scientist at the European Research Infrastructure BBMRI-ERIC. She has a background in sociology (doctorate with honours), with a focus on science and technology studies (STS), gender studies and qualitative research methods. Her dissertation was awarded the prize for best thesis in 2017 by the research network "Gender and Agency" of the University of Vienna. She is visiting researcher at Newcastle University, and she has worked as lecturer at the University of Vienna and Malta. Her current research focus in the field of Biographymedical research is on the ethical and societal implications of health data sharing and medical artificial intelligence. She is leading the "Ethics of AI Lab" within BBMRI-ERIC. She is ethics advisor and member of the ethics and legal advisory board in large European projects.

23. Lukas J. Meier, University of Cambridge. Outsourcing Medical Ethics to AI.

Artificial intelligence helps medical staff with a multitude of labour-intensive duties, including precision dosing, predicting long-term therapeutic outcomes, and interpreting medical images; ethical tasks have so far been excluded from 18utomatization. With the COVID-19 pandemic, however, the need for the taking of thousands of morally relevant decisions within short time frames arose.

Expanding the use of artificial intelligence into the realm of clinical ethics suddenly seemed a worthwhile enterprise. Our interdisciplinary team of doctors, engineers, and ethicists developed the world's first universal medical-ethics advisory system. Published as a Target Article in the American Journal of Biographyethics, it has sparked off a lively international debate. I will begin this talk by explaining how we used machine learning to incorporate Beauchamp and Childress' prima-facie principles as the ethical basis and discuss how we acquired suitable training data and provided the algorithm with input categories to capture the parameters of individual medical cases. I shall also show the user interface and demonstrate how the algorithm works on an example case. Preliminary performance results are promising. That one can do something, however, does not imply that one also should: would it really be prudent to outsource medical ethics to artificial intelligence?

Lukas J. Meier is a Junior Research Fellow at the University of Cambridge with main interests in medical ethics, neurophilosophy, and artificial intelligence. He studied philosophy at the University of Oxford and linked the topic of brain death to the debate on personal identity in his doctoral thesis. In Cambridge, Lukas teaches in ethics, metaphysics, philosophy of mind, and political philosophy. Churchill College

24. Petra Müllerová, Lund University. Ethical principles considering mental health applications using AI.

Mental health applications have become part of people's smartphones, especially during the Covid-19 pandemic. Up to 36% of adults use them. Due to the frequent use of AI in the framework of these applications, we decided to investigate whether they correspond to the ethical principles developed by the WHO for using AI in healthcare. We tested 20 applications aimed at treating depression. We subjected them to six fundamental principles from the user's perspective: Protecting human autonomy; Promoting human safety, Ensuring transparency and intelligibility; Fostering responsibility and accountability; Ensuring inclusiveness; Promoting responsive AI. We have identified the three most alarming ethical problems. 1. Using the application's user to train the AI learning machine system in the mental health field without their informed consent. 2. Personalizing the AI chatbot to establish a close relationship with the vulnerable user to bind the user to use the given application. 3. Absence of liability in the event of harm to the user's health in the field of mental health. Based on our

research in these areas, the investigated applications violate four of the six fundamental ethical criteria for AI in healthcare.

Petra Müllerová is a postdoc at the Health Law Research Centre of the Faculty of Law at Lund University. The EUGLOHRIA finances her postdoc position. Therefore, her postdoctoral project focuses on pandemic-related research. Petra's postdoc project title is: "How the lack of legislation and ethics interferes with citizens' rights in the development of eHealth in the background of the COVID-19 pandemic?" She already started to deal with the scope of medical law in her doctoral thesis entitled: „The development of telemedicine in the context of cross-border healthcare services in the European Union: comparative approach France / Czech Republic". After her doctoral studies, she deepened her knowledge of European law and the actual drafting of European legislation.

25. Kajsa Norbäck, Uppsala Universitet. Research ethics committee members' perspectives on paediatric research: a qualitative interview study.

Research ethics committees (RECs) have a crucial role in protecting children in research. However, studies on REC members' ethical perspectives on paediatric research are scarce. We conducted a qualitative interview study to explore REC members' ethical values, challenges, and potential for improvement of ethical aspects in applications involving children with severe diseases. The REC members considered that promoting autonomy, protecting children's wellbeing and integrity, and regulatory adherence were important but sometimes challenging. They expressed concerns about the quality of information for children, dependency, vulnerability and honesty, as well as the voluntary nature of participation, and conflict of interests. Best practices for information and assent, informed by children's perspectives and contextual vulnerability, may help paediatric researchers and RECs promote autonomy, ensure protection, and decrease vulnerability.

Kajsa Norbäck is a PhD Candidate at the Centre for Research Ethics & Bioethics (CRB) at Uppsala University. She holds a Bachelor's and Master's degree in Psychology. Her PhD project empirically explores ethical aspects of recruiting children with cancer to research studies, including ethical values and challenges related to consent- and assent processes. Using qualitative methods combined with normative ethical analysis, she explores recruitment from the perspectives of health care professionals and researchers, ethical review board members and children with cancer and their parents.

26. Lars Sandman, Linköping University and Moa Dahlin, Uppsala University. JUST SEVERITY - an interdisciplinary project on disease severity in healthcare priority setting.

The concept of how badly off an individual is in terms of ill health (severity) plays an essential role when prioritizing which patients should get treated or not in a budget-constrained healthcare sector. Some healthcare jurisdictions start with explicit ethical principles (e.g. the Swedish, Norwegian and Dutch), where assessment of severity is essential for whether patients get access to treatments, by accepting a higher cost per health benefit the more severe a patient´s condition is. Despite its prominent role in today´s healthcare decision-making severity is an undertheorized and contested concept, with an unclear normative rationale. This has resulted in a multifaceted, and conflicting understanding and use of severity, with no or little relation to the strong development within general theories of distributive justice during the last few years, and with unclear consequences regarding the distribution of healthcare resources and population health. In a healthcare system struggling with prioritizing scarce resources decision-makers call for developed and more concrete normative principles, of which severity is a central part. In this session we will present the overall approach of the project JUST SEVERITY where the aim is to develop a more normatively robust conceptualization of severity. The project combines normative analyses with health economic modelling and legal analysis and besides presenting an overview of the project and its' different sub-studies, three specific studies will be presented in more detail. At the end we will provide a legal comment on severity in the Swedish healthcare jurisdiction.

Lars Sandman is professor of healthcare ethics and director of the National Centre for Priorities in Health at Linköping university. His research focus on the ethics of priority setting and he is an ethics consultant to Swedish healthcare authorities and care providers.
Moa Dahlin is associate professor and senior lecturer in public law at Uppsala University.

27. Lena Wahlberg, Lund University. Strain at a gnat and swallow a camel? Over- and underinclusiveness of the Swedish legal requirements for ethical review.

Over the last few years, the Swedish ethical review system has received harsh criticism. Critical voices from the humanities and social sciences have complained that the system is designed for medical research and does not fit

well with the methods and questions that are relevant in other disciplines. It has been pointed out that the area of application of the Swedish Ethical Review Act (2003:460) is extremely broad, with the result that also research where the ethical risks are relatively small needs to be subjected to costly prior review. The presentation will problematize the relationship between the purpose and the scope of the Ethical Review Act, with a particular focus on areas where the current formulations of the act's area of application are either over- or under-inclusive vis-à-vis its purpose to protect individual human beings and human dignity. We will also present a recently initiated research project that aims to evaluate the appropriateness of the Ethical Review Act for research in the humanities and social sciences.

Lena Wahlberg, Associate professor of jurisprudence specializing in medical Law, Faculty of law, Lund University.