EACME

EUROPEAN ASSOCIATION
OF CENTRES OF MEDICAL ETHICS

EACME Conference 2025

Book of Abstracts

Venue: Gebäude AFL
Affolternstrasse 56
8050 Zürich

Plenary Session I

Rieke van der Graaf

Bio*:* Rieke van der Graaf is an associate professor of Bioethics, with a special focus on research ethics, the ethics of gene therapies and global health ethics. She is the head of the Bioethics and Health Humanities department at the Julius Center of the UMC Utrecht. She is co-director of the WHO Collaborating Center for Bioethics. She is a member of various committees, including the Dutch Health Council, and the Central Committee on Research Involving Human Subjects in the Netherlands.

Title: "Moonshots and miracles – how to ethically navigate the gene therapy debate"

Abstract: Gene therapy currently raises high societal expectations. At the core of these therapies lie ethical assumptions about hope, healing, and the potential for cure. Some gene therapies have also shown to be very successful and be able to significantly improve the quality of life of individuals. Gene therapies are sometimes presented as moonshots, showing the direction in which science should develop and patients expect to be cured. Some successful examples of gene therapy are also presented as miracles. I will argue that there's an interesting analogy between gene therapy and miracles as we know them from the Christian tradition, with sudden cures of diseases that were previously impossible to be cured, faith in the therapy and the healing power of physicians. I will argue that framing gene therapies as moonshots and miracles can have implications for at least three ethical aspects in the gene therapy discussion that are currently underemphasized: not offering false hope, ensuring equitable access (not everyone can be cured), and the social value of gene therapy.

Plenary Session II

Bjørn Hofmann

Bio: Bjørn Hofmann is a Norwegian professor in philosophy of medicine and bioethics with special interest for the relationship between epistemology and ethics. He is affiliated with and the Centre for Medical Ethics at the University of Oslo in Norway and the Department of Health Science at the Norwegian University of Science and Technology (NTNU) at Gjøvik. Hofmann is trained in the natural sciences (electrical engineering and biomedical technology), history of ideas, and philosophy. His main subjects and interests are basic concepts for health care, norms of knowledge and evidence production, the theory and practice of governing technology, health services research, and (bio)medical ethics.

Title: "What does scientific responsibility and integrity mean in times of polarized and politicized research?"

Abstract: Research has become ever more polarized and politicized. This poses basic challenges to scientific responsibility and integrity. In this keynote lecture Bjørn Hofmann will characterize polarization and politization in research. He will then discuss the implications for research ethics in terms of responsibility and integrity. In order to point to ways to promote scientific responsibility and integrity, Hofmann will investigate drivers and facilitators of polarization and politization.

Plenary Session III

Katrien Devolder

Bio: Katrien Devolder is Professor of Applied Ethics and Director of Public Philosophy at the Uehiro Oxford Institute, and a Fellow at Reuben College, University of Oxford. Her work has mainly focussed on the ethics of cloning, stem cell research, gene editing in humans and animals, medical complicity, and the role of compromise in bioethical debate. Her most recent project explores the meaning and impact of judgments about laziness through community engagement and research (https://www.projectlazy.co.uk). She produces (conducts, films and edits) interviews with academics to make complex ethical debates accessible to a wide audience (Uehiro Oxford Institute YouTube Channel/Thinking Out Loud podcast) and engages with diverse communities, including children, to foster critical thinking and meaningful dialogue around ethical issues.

Title: "When Slowing Down Creates Value"

Abstract: Healthcare innovation and research often prioritises acceleration and efficiency. This talk challenges this paradigm by examining how slowing down can result in more meaningful and beneficial outcomes. Drawing on examples from medical research and community engagement initiatives, and my own research on judgments about laziness, effort, and productivity, I distinguish between justified slowness and mere delay. Pacing in research and innovation leads to more ethically sound and effective healthcare advancements but there are challenges in determining when deliberate pacing creates value.

Plenary Session IV

Maria do Céu Patrão Neves

Bio: Maria do Céu Patrão Neves is Full Professor of Ethics of the University of the Azores (Portugal), President of the National Council of Ethics for the Life Sciences (Portugal), Vice-chair of the European Group of Ethics in Science and New Technologies (EGE, European Commission), Member Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO, Council of Europe), of the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST, UNESCO), of the Lisbon Academy of Sciences. She was consultant on Ethics of Life for the President of the Portuguese Republic, Member of the Board of Directors of the International Association of Bioethics. Currently she teaches at different Universities and is a member of several Ethics Committees, also coordinating international projects, namely within Africa-EU partnership. Ethics expert and project evaluator for the European Commission, and Ethics Advisor and Chair of Ethics Advisory Boards (EAC) of several European Research Projects. Authored and/or coordinated 38 books, including the 13-volume collection dedicated to Applied Ethics (2016-2018), and the Dictionary of Global Bioethics, with Henk ten Have (2021), and hundreds of papers, delivered over 400 conferences. She is a regular columnist in regional and national journals. Member of the European Parliament (2009-2014).

Title: "Towards a global health approach: the challenges for One Health"

Abstract: Broad visions, to encompass diversity, and articulated visions, to present an integrated picture, are the best approach for deeply understanding the surrounding reality, being also a fundamental basis for acting effectively on the problems that arise.
This is also the case in the field of health. The holistic approach to health began to be recommended by the World Health Organization in 1948, in its definition of health (widely criticized at the time, remaining controversial for decades); the most recent step in pursuing this path was the proposal for One Health (generally well accepted, which is a sign of the times). One Health is a holistic and integrated approach that recognizes the interconnection between the health of humans, animals, plants, and their shared environment (ecosystems), currently considered by the WHO as crucial for preventing and responding to

global health threats like pandemics. This approach, if well and fully implemented on the field, could have avoided or minimized the impact of several epidemics/pandemics of the 21st century (e.g. H5N1 Avian Influenza, SARS, H1N1 Influenza / Swine Flu, MERS, Ebola, Zika, COVID-19, Monkeypox). There are currently several international programs seeking to implement the One Health perspective. However, this has proved to be quite difficult and challenging. The challenges are of different nature – e.g. scientific, terminological and methodological, regulatory –, arise on different levels – e.g. political, institutional, professional –, and require different types of intervention – e.g. communication, collaboration, coordination. In this talk we will try to present the specific nature of the One Health approach, defining the concept and outlining its scope (what is it?); explain the origin of its formulation, highlighting the context and objectives of its proposal (how and why did it come about?); and point out the requirements for its successful implementation, identifying the important challenges that its deployment poses (how is it operationalized?)

Itinerare Round Table Discussion

Participants: Janine Reichenbach, Jasmin Barman-Aksözen, Johannes Häberle, Julian März

Title: When Innovation Outpaces Implementation. Between acceleration and responsibility: Opening a dialogue between rare disease research and medical ethics

Abstract: Health care innovation is transforming rapidly, driven by scientific and technological progress. Yet, translating promising discoveries into clinical benefit remains complex and often slow; a challenge that is particularly delicate in rare disease research. While gene therapies and other emerging technologies hold unprecedented promise for patient treatment, their implementation often lags behind, leaving many affected waiting for access. These difficulties are compounded by the heterogeneity of rare diseases, regulatory hurdles, and the need to balance innovation with patient safety. In line with this year's EACME Annual Conference theme "Responsible Innovation: Ethical Perspectives on Health Care Research and Practice", this round table brings together researchers from the University of Zurich's Research Priority Program *ITINERARE – Innovative Therapies in Rare Diseases*. A group of four experts – covering metabolic diseases, somatic gene therapies, law and regulation, and a *scientist-patient* perspective – will address topics including clinical trial design, evidence-based medicine, access to therapies, the ethics of risk, and other legal and societal implications. Their contributions will highlight the real-life challenges of translating innovation from bench to bedside and explore the ethical, regulatory, and practical dimensions of responsible implementation. The session will conclude with a Q&A, fostering dialogue between medical ethics experts and rare disease researchers.

Parallel Sessions I

AI, digital twins and the reconfiguration of health and identity (AFL-E-015)

Giuseppe Comerci

Title: Ethical Challenges of Digital Brain Twins for Personalized Medicine

Abstract: A DT is a real-time virtual representation of a real entity, designed to improve and monitor the functioning of the represented object over time. DTs have gained attention in precision medicine, as they allow for personalized simulations of a patient's organ, helping to optimize clinical efficacy. In fact, thanks to advanced algorithms and machine learning, a DT can offer a diagnosis, predict disease progression, and suggest therapies. The implementation of DTs in medicine has sparked a fruitful debate about their ethical implications. However, limited attention has been given to the ethical issues related to DTs designed to replicate the human brain, namely digital brain twins (DBTs). Recent research in neuroethics has shown that research involving the brain raises unique ethical challenges. Given the limited literature on this topic and

the growing number of projects developing and testing DBTs, a better understanding of the ethical issues surrounding this technology is needed. To achieve this aim, I conducted a double-scoping review based on the method outlined by Arksey and O'Malley. The first scoping review focused on the ethical issues of general DTs in medicine, while the second focused on the ethical issues of brain-computer interfaces (BCIs) in medicine. BCIs are a well-known neurotechnology widely discussed for their ethical implications and share semantic, definitional, and operational similarities with DBTs—so much so that DBTs can be considered a type of BCI designed for simulation purposes. Thus, BCI ethical literature represents a suitable source to inform us about the potential ethical challenges that may arise from the development and application of DBTs in medicine. By cross-referencing the specific medical ethical issues of DTs with those associated with BCIs, it is possible to anticipate potential ethical concerns regarding DBTs. Preliminary results suggest that a DBT may entail changes in identity and personality due to the interaction between the patient and their brain simulation. Moreover, DBTs may play a role in end-of-life decision-making associated with disorders of consciousness, and they could also hinder patient agency. DBTs are a promising technology that can improve the management of several neurological and psychiatric diseases. However, their benefits may not come without risks, and this research can help anticipate possible ethical issues that need to be addressed when implementing this technology in clinical practice.

Georg Lindinger

Title: Patients' Perspectives on Use of Artificial Intelligence and Personalised Risk Prediction to prevent sudden cardiac death – Results and Reflections from a European Study in Empirical Ethics

Abstract: The goal of our contribution is to present findings from both completed and ongoing research within an international initiative – the PROFID project – dedicated to enhancing the prevention of sudden cardiac death following myocardial infarction through defibrillator implantation on a European scale. Therefore, we outline our transdisciplinary empirical ethics approach and discuss (interim) results of three distinct but interrelated studies. Our interdisciplinary research team – comprising experts in health sciences, health economics, medicine, (medical and technology) ethics, sociology, and social sciences – investigates patient perspectives on innovations of Personalised Medicine and Artificial Intelligence (AI) in healthcare and explores different stakeholder viewpoints as well as broader ethical and societal dimensions. Our aim is to systematically analyse the views of cardiac patients (with and without ICD) and Healthcare Professionals on AI-driven applications and Personalised Risk Prediction Models, assessing their ethical implications in conjunction with considerations of Non-Inferiority Trials across six European countries (Germany, the Netherlands, the United Kingdom, Spain, Denmark, and the Czech Republic). The Outcomes are based on: (1) Intermediate findings from an ongoing multinational survey study involving these European countries. (2) An interview study to exploring patients' perspectives on AI-driven ICD care in Germany and the Netherlands conducted in collaboration with medical ethicists from Academic Medical Center (AMC). This empirical study was completed, and its results were published in April 2024 under the title "Ethical use of artificial intelligence to prevent sudden cardiac death: an interview study of patient perspectives" in BMC Medical Ethics. (3) A systematic review examining healthcare providers' views on Artificial Intelligence in medicine titled "Healthcare Professionals' Perspectives on Artificial Intelligence in Patient Care: A Systematic Review of Hindering and Facilitating Factors on Different Levels" has been submitted to BMC Health Services Research and is currently forthcoming. In conclusion, we demonstrate the benefits of combining social science research with ethical inquiry to foster a dynamic, iterative integration of descriptive and normative perspectives.

Felicitas Holzer

Title: On the normative status of “mental privacy” rights

Abstract: Mental privacy is becoming an increasingly pressing ethical and legal concern as neurotechnological approaches to decoding and manipulating human brain activity advance. The notion of mental privacy emphasizes the importance of safeguarding personal thoughts, emotions, and mental states from potential intrusion via brain-computer interfaces, neuromarketing tools, neuroenhancement, and other mindreading devices. The misuse of sensitive brain data and AI-driven profiling of mental states pose significant privacy risks. Additional challenges include defining consent requirements and coping with uncertainties about potential future inferences from mental data. In recent debates, mental privacy is generally framed as a new kind of “neuroright”. However, there is considerable debate and conceptual ambiguity regarding the notions of 'privacy' and 'the mental' that underpin this proclaimed right. It has been questioned whether the right to mental privacy represents a substantive addition to existing privacy frameworks or merely a rearticulation of established concerns. While proponents see a specific concern that mental privacy is directly linked to personal identity and autonomy, and emphasize the uniqueness of mental data, critics argue that mental privacy rights either significantly overlap with familiar privacy concerns or, on closer inspection, reduce them to familiar privacy concerns. This paper examines the normative foundations of mental privacy and considers whether it represents a significant normative shift in the concept of privacy. Specifically, we consider how the inclusion of the 'mental', drawing on theories of the mind, extends the traditional boundaries of the privacy debate, and whether mental privacy introduces a new moral foundation distinct from general privacy concerns. Our analysis shows that the philosophical literature on the 'nature' of the 'mental' challenges simplistic assumptions about mental privacy based on a narrow view of the theory of the mind. We argue, however, that privacy concerns about our feelings and inner experiences are at the heart of privacy concerns, which may give us reasons to defend mental privacy as a neuroright on pragmatic grounds.

Rasita Vinay

Title: GRACE: towards trustworthy AI principles in a voice assistant with older adults, a pilot study

Abstract: Background: As one of the leading causes of disability among older adults, dementia poses a large health and economic burden on individuals and societies globally. Faced with healthcare worker and caregiver shortage, providing care to people with dementia (PWD) poses significant burden on family members and other informal caregivers. To meet the basic needs of PWD living in the community, informal caregiver’s are negative impacted regarding their own physical health, social life, and financial status. While the global economic burden of dementia care was estimated at US$1.3 billion in 2019, 50% of these costs were related to informal caregiving. In order to ease caregiver burden, we must utilize technologies such as voice assistants, to provide certain health interventions that can help promote aging-in-place and independence of PWD. Objective: To determine the perceptions towards an AI-based voice assistant for PWD, GRACE, among healthy older adults in a pilot study. Method: A small pilot study was conducted with 21 healthy older adults (over 60 years of age) between August - November, 2024 in Zurich, Switzerland. Participants received an intervention with GRACE, followed by an interview based on the EU’s Assessment List for Trustworthy AI (ALTAI) checklist. Results: 13 female and 8 male older adults, with an average age of 69 years, participated in this pilot study. Regarding the interaction with GRACE, most participants reported it to be clear and unambiguous, easy to use, useful and felt easily understood. They suggested further improvements regarding the delay and communication aspects, as well to provide more exercises and personalization. In response to the ALTAI questions, most prevalent answers were regarding positive machine awareness, information sharing, equal treatment, sufficient oversight and decision-support. Conclusion: Overall, participants found GRACE to be a useful tool for PWD to use in their own homes, and had a lot of constructive feedback regarding the technology, interactions, interventions, general appearance and characteristics of GRACE. Responses to the ALTAI-based interview showed the awareness of older adults of trustworthy AI principles, and a positive recognition of these ethical aspects within the GRACE prototype.

The results from this interview study will be used to guide future iterations of GRACE, in a participatory design involving PWD and their carers.

Andrew Barnhart

Title: Disabling Digital Twins: A need for disability perspectives in the ethics of digital twins

Abstract: Digital twin technology has emerged as a promising tool in precision medicine, offering personalized health interventions through real-time patient simulations. Ethical engagement with digital twins, however, has largely overlooked disability-specific concerns. This is problematic given that one of the potentially largest end-users of digital twins will be individuals with disabilities. Current literature indicates that digital twin applications often rely on a narrowly defined medical model that conflates disease with disability and reinforces ableist norms, thereby excluding the diverse experiences of impairment. In healthcare contexts, digital twins analyze complex medical data to predict health outcomes but may inadvertently marginalize individuals with disabilities by neglecting social, environmental, and embodied dimensions. Ethical challenges from bodily variation, societal narratives, and equitable access are further compounded by the risk of technoableism, wherein technological advancements unintentionally perpetuate discrimination. Drawing on insights from disability studies and disability bioethics, this exploration underscores the necessity of shifting toward a more inclusive framework that embraces diverse models of disability. Engaging disabled stakeholders through collaborative and participatory design practices can ensure that digital twin technologies authentically reflect the lived realities of individuals with disabilities and avoid default assumptions rooted in traditional medical models. Prioritizing accessibility, respect for difference, and empowerment in design promises to reframe normative standards of health. Ongoing interdisciplinary dialogue and rigorous evaluation of emerging digital infrastructures are essential to safeguard equitable access and ensure that the benefits of digital twin technology are shared by all members of society.

One Health (AFL-E-011)

Lorina Buhr

Title: AI innovation in healthcare as a threat to planetary health? A proposal for the (non-) justifiability of AI technology and applications.

Abstract: Artificial intelligence (AI) systems are extremely resource intensive. From the material basis of the hardware to the training of AI systems and the AI-supported software application, energy, water and rare earths are increasingly required. For instance, AI-supported search queries on the internet consume many times more electricity than standard search engines. This electricity consumption is in turn associated with CO2 emissions, which contribute to anthropogenic climate change. Additionally, the resource extraction (rare earths and minerals) for digital technologies and devices can lead to severe ecosystem damage and habitat destruction. Thus, AI systems have the potential to harm planetary health and jeopardize interspecies justice. It is often emphasized that AI can potentially contribute to a better energy balance by increasing efficiency. However, it is not yet evident that the potential savings through AI could overcompensate for the consumption in the innovation chain. In addition, parts of the environmental problem of AI are often externalised to countries in the Global South. AI systems therefore have a negative C02 and ecological profile and lead to new social injustices. Against this backdrop, to what extent can the push for more digitalization, digital innovation, and the use of AI in healthcare still be justified? In the ethics of AI literature, concepts such as ‘Sustainable AI’ and ‘Green AI’ have recently emerged to address the environmental problem of AI systems. According to these proposals, AI should become more ‘sustainable.’ I am taking an alternative perspective. To this end, I draw on climate ethics literature on the budgeting of greenhouse gas emissions and the distinction between types of greenhouse gas emissions. Climate ethicists distinguish between 'subsistence' and 'transition' emissions, which are necessary for technological development, and 'luxury' emissions. It is argued that the latter no longer hold any ethical justification in the

face of global warming. I argue that various objectives of digital technological innovation and application in the healthcare system can be distinguished, and that these objectives correlate with different levels of ethical justifiability. For example, digitalization is essential and justifiable when it supports the subsistence of the healthcare system, but this is less true for AI applications that are not critical for basic care and medical research, such as non-evidence-based health apps.

Orhan Önder

Title: Sustainable Health Through Sustainable AI: Sustainability From Public Health to Planetary Health

Abstract: The growing planetary poly-crisis—marked by climate change, ecological degradation, and planetary health inequities— necessitates a fundamental transformation in healthcare systems. This paper examines the historical progression of health systems from public health to planetary health, where human well-being is understood within the limits of planetary boundaries. Planetary health provides a framework for sustainable health systems that reduce disease burden, optimize care delivery, and decarbonize healthcare operations. Within this context, artificial intelligence (AI) emerges as a transformative tool for addressing healthcare sustainability. AI applications offer significant potential to optimize resource use, improve preventive care, and enable circular economies in healthcare, thereby facilitating the transition toward planetary health. However, AI poses environmental challenges, including high energy consumption and resource-intensive development processes. To ensure its long-term viability, AI must align with sustainability principles—what Aimee van Wynsberghe terms sustainable AI—by minimizing its ecological footprint while enhancing ecological integrity and social justice. This paper contributes to the literature in three key ways: (1) it traces the transition of health systems toward planetary health, contextualizing the role of sustainability; (2) it explores emerging AI applications in fostering healthcare sustainability within the planetary health framework, and (3) it argues for the necessity of sustainable AI, ensuring AI technologies themselves do not exacerbate ecological crises. By positioning AI as both a solution and a subject of scrutiny, this study advances the discourse on AI's potential for planetary health.

Silvia Salardi

Title: What is the role of institutional bioethics in addressing new technological challenges: the case of the ecological and carbon footprint of the healthcare sector

Abstract: The paper proposes a philosophical-legal reflection on how Bioethics could be pivotal in addressing the ecological and carbon footprint of the healthcare sector practices and activities as well as of healthcare professionals. As is well-known, the healthcare sector is a significant contributor to climate change and environmental pollution. In our view, Bioethics can play a relevant role in adequately addressing the ethical paradox between the healing mission of the healthcare sector and its negative impacts on environment and climate. This can be achieved in two ways: 1) by widening the bioethical reflection to include the environmental responsibility of clinicians and health care professionals (i.e. reducing the demand for health care services or the large amounts of single-use medical devices and disposable supplies) based on their duty to avoid harm (non-maleficence); 2) by operationally integrating principles and values, which guide public health ethics and bioethics, to create an environmentally sustainable ethical framework enhanced with measures to contrast the climate and environmental disaster at all levels (individual and organizational levels). This integration will work if the different actors' roles regarding climate change and environmental issues are considered as having specific needs, which however are interconnected. Indeed, the roles of organizations and of workers vary greatly as well as their needs and knowledge levels for climate and environmental information. However, their cooperation is essential to success. Thus, to respect the do not harm principle in this wider meaning requires massive education and training of all those involved in the health care sector. This because every actor in the health care must contribute to respect for the right to health, which in turn is the essential reason for not doing

environmental harm. The recognition of the right to a clean, healthy, and sustainable environment as a human right by the 2022 UNO Resolution will be the general framework for our reflection on prioritization of environmental non-maleficence both at the organizational and the individual level.

Gabrielle Samuel

Title: Environmentally Sustainable HeAlth REsearch (SHARE): From 'tool solutionism' to a context sensitive, just, systems focused and reflexive approach

Abstract: Health research is a significant contributor to climate change and other adverse environmental degradation. Wet labs, where experimental work involving chemicals and biological materials takes place, consume large quantities of water, reagents, and single-use plastics. Dry labs—spaces dedicated to data collection, analysis, and computational research—contribute to environmental harms through the substantial energy required to generate, store, and process data, as well as harms associated with mining, manufacture and electronic waste associated with digital hardware and infrastructures. Clinical trials are associated with greenhouse gas emissions, and depending on the trial, also other environment harms, such as the production of hazardous and non-hazardous waste materials, including from pharmaceuticals, air pollution due to road travel, and water use. Together, these health research environmental harms contribute to human (ill)health through the environmental determinants of health. Numerous tools have been developed to enable and encourage researchers to assess and reduce health research environmental harms, including guidelines, carbon calculators, and certification systems. However, these tools raise potential ethical, social and practical issues. We have embarked on a project that aims to explore these concerns by adopting a multi-country approach. In this paper, we will map out the key ethical, social and practical issues, including tensions with local values when tools are used in different contexts; issues of inequity and injustice, particularly in global health research; and a lack of space for research communities to reflect on possible short- and/or long-term unintended consequences that using such tools might have on wider systems. We will argue that because of these concerns, we must not fall into a "tool-solutionist" fallacy, investing resources into developing tools without paying equal attention to their potential negative implications. Furthermore, we must develop guidance for tool use that does not impose a (Western) perspective on other research ecosystems, but includes at the earliest stage, a diversity of inputs from communities in other contexts. We will then map out how we will attempt to explore and address these issues in our project.

Sabine Salloch

Title: Planetary Health Research Ethics: Sounding out the Dimensions

Abstract: The degradation of natural environments has an enormous impact on human health, which is further specified within the transdisciplinary research paradigm of planetary health. Planetary health situates human health within human systems and, at the same time, it considers the natural systems within which our species exists. Bioethical debates so far have predominantly discussed ecological trade-offs in clinical decision-making, whereas the intersection of research ethics and planetary health remains rather unexplored. Relevant codices to date tend to reduce environmental issues to emissions directly caused by research activities. From an analytical and practical perspective, however, there are much more ethical issues to be considered that are linked to sustainability and biomedical or clinical research. The talk introduces the concept of planetary health research ethics that better accounts for the many-faceted dimensions that emerge in this intersection. After making some theoretical underpinnings of research ethics explicit, health research as a threat to the environment is discussed as it is linked to potential trade-offs between scientific quality and ecological sustainability. However, there are also co-benefits between both aims that deserve further attention. As a second point, the generation of evidence for a greener health-care practice is highlighted which is also related to mitigation. Thirdly, and in terms of adaptation, research on

the environmental impacts on specific diseases is analyzed in its ethical dimension. The talk closes with concrete suggestions for research ethics assessment considering the complexity of planetary health.

Aging, Autonomy, and Ethics: Rethinking Care and Technology in Later Life (AFL-E-022)

Kasper Kruithof

Title: Digital assistive technologies to support community-dwelling older adults: an interpretative synthesis of experienced benefits and harms

Abstract: Background: Digital assistive technology (DigAT) holds promise for reducing healthcare costs, improving access to care, and supporting independent living for older adults. However, realizing these benefits remains challenging as seemingly effective and cost-efficient forms of DigAT often fail in real-world settings due to misalignment with users' needs, values and practices. With the ultimate aim of contributing to more effective DigAT use among community-dwelling older adults, we explored the benefits and harms they experienced using DigAT. Methods: We systematically searched PubMed, CINAHL, Philosopher's Index, and PsycINFO for qualitative studies on community-dwelling older adults' experiences with several forms of DigAT, and conducted an interpretative synthesis of thirty-one studies. Results: As intended, DigAT resulted in experienced benefits related to health, safety, self-reliance, wellbeing, motivation, empowerment, and access to care. Autonomy and independence were mostly framed as aspirational benefits, dependent on maintaining health and safety to age-in-place. Unexpected benefits of DigAT included pride, self-confidence, feeling cared for, social inclusion, and improved perception of quality of dying. However, users also reported various harms, including perceived unsafety, concerns about burdening others or being burdened, privacy concerns, feeling controlled and judged, alienation, powerlessness, loneliness, stigma, and emotional distress. Studies on surveillance-oriented DigAT (e.g., tracking or monitoring technologies) reported a broader range of harms. When DigAT did not align with users' needs, values, or practices, it resulted in misuse, non-use, or adapted use. Conclusions: Our synthesis of benefits and harms clarifies questions regarding proportionality and subsidiarity and offers guidance for welfare organizations in adopting a more intentional approach to DigAT design and implementation. Such an intentional approach should start from the premise that DigAT needs to align with older adults' needs, practices and values. This could enhance the adoption and effectiveness of DigAT, ultimately supporting its broader goals of improving access, reducing costs, and promoting independent living.

Mia Svantesson

Title: High-end medicine: Very old patients need palliative care, not intensive care – in line with the priority-setting principle Need-Solidarity

Abstract: Background: ICU-admissions for older patients are rising, constituting a challenge for already pressurised healthcare. Decision making about ICU admission in times of limited resources may provide important knowledge about difficult prioritisations. Thus, the aim was to investigate ICU-admission decisions for older patients with COVID-19 regarding justifications and influencing factors. Methods: A mixed-methods approach was used. COVID Rounds and Moral Case Deliberations (n=19), regarding 34 patients in three Swedish hospitals during the pandemic were audio-recorded. Data were also collected from medical records of 329 patients aged ≥65 years diagnosed with COVID-19. Qualitative analysis of justifications of decisions in all data-sources. Multiple regression analysis was used to investigate whether sex, age, pandemic wave, comorbidity and frailty were associated with ICU-admission in medical records. Findings: Justifications for or against ICU-admission included considerations of medical benefit (too ill/not too ill), general condition (good/frail), professional duty (benefit of the doubt/do no harm), "worth giving it a go" (will to live and grit/lack of will and coping) and age (high age/not too old). On the conference we will

focus on age≥80, the only factor significantly associated with not being admitted to ICU. Normative conclusion: We suggest offering palliative care instead of ICU-care to very old patients, aligning with the principles of Non-maleficence and Justice as well as the Swedish legal priority-setting principle Need-Solidarity. Regardless of the interpretation of the Four Principles or Swedish prioritisation guidelines, we still have a strong case for considering chronological age in ICU-admission decisions. The Swedish principle Need-Solidarity offers a virtuous dimension to distributive justice, suggesting that very old patients may need palliative rather than ICU-care. As one intensivist informant noted, "Ninety feels like, if you've had a good life and you're spry and healthy... if you die suddenly, then it's expected... And better than dragging to the ICU and tormenting the person." However, palliative care may still include intermediate care (no ventilator) if the goal is quality-of-life.

Kim Kulaczewski

Title: Responsible use of innovative technology in residential care for people with dementia - A human-rights approach

Abstract: Providing care for individuals with dementia presents a significant challenge within the healthcare system. Beyond the symptoms of dementia, including confusion, disorientation, and increased restlessness, the growing shortage of healthcare professionals exacerbates the workload for professional care staff. In response, technological innovations are increasingly being endorsed to support care delivery, including the implementations of technologies that restrict the freedom of movement of residents in care facilities. While these technologies hold considerable potential to enhance the quality of care for people with dementia and reduce staffs' workload, they also give rise to legal and ethical considerations, particularly concerning freedom and basic rights of residents. This presentation aims to elaborate on the types of technology that are implemented in nursing homes and highlights their perceptions by members of staff in light of human rights. Empirical data stems from an exploratory mixed method study on the use of restraints in residential dementia care which was conducted in five care facilities with a dementia focus. During stakeholder interviews and participant observations, (the implementation of) innovative technologies emerged as a recurring topic. Particularly, the use of technologies that are related to movement such as trick locks and GPS trackers appeared pertinent and constitute the focus of the presentation. This raise concerns regarding the right to freedom of movement, since they often restrict the residents' ability to navigate their environment independently. Moreover, such technologies can infringe upon the fundamental right to privacy, as devices such as GPS trackers involve constant surveillance of residents. While these technologies are commonly justified by the need to ensure safety and security – both of which are recognized as human right by the UN - they also create potential conflicts with other fundamental rights. A significant concern is that many of these technologies are implemented without the residents' explicit awareness or informed consent. Consequently, this raises additional ethical issues regarding the right to autonomy and the capacity to provide informed consent. In light of these findings, the presentation will conclude with a discussion of the ethical implications surrounding the responsible use of technology in inpatient care emphasizing the need for a balanced approach that respects fundamental human rights.

Charlotte Graafland

Title: Developing a counseling protocol for responsible biomarker disclosure in frontotemporal dementia

Abstract: Frontotemporal dementia (FTD) is a devastating progressive disease that causes behavioral changes, language impairments and/or motoric problems. It is genetically heritable in 20-30% of cases, but age of onset in genetic forms is unpredictable and ranges from 35 to >80. The research field of genetic FTD is developing "onset-predictive biomarker tests" (OPBTs), that could predict whether dementia symptoms are likely to occur in the next few years in carriers of a genetic variant that causes FTD. These OPBTs are useful

for eligibility screening for clinical trials. However, the implementation of OPBTs in clinical trial recruitment raises ethical issues, e.g., around the psychological and societal impacts of onset predictions, informed consent, or the right not to know. This is especially challenging in individuals at 50% risk of carrying the genetic variant who have not learned whether they are carriers, for a positive OPBT result would at once communicate both their genetic status and the imminence of symptom onset. There is a need for ethical guidance on how to responsibly implement disclosure of OPBT results in FTD clinical trial recruitment. We have developed a counseling protocol for disclosure of OPBT results. To this end, we first analyzed (dis)analogies with counseling guidelines in pre-symptomatic genetic testing for neurodegenerative disease and in biomarker testing in Alzheimer's disease. We then drew on our previously conducted qualitative study of the perspectives of people at risk of genetic FTD on OPBT, to develop a disclosure protocol tailored to genetic FTD. Challenges in this process included having to discern relevant differences between disclosure in a research vs. clinical context; designing a protocol that was specific enough to provide guidance, but also sufficiently widely applicable to be used in various contexts and for various types of biomarkers; developing standardized language to make complex risk information comprehensible to lay persons; and taking into account cultural and international differences in healthcare systems and counseling preferences. When our counseling protocol is implemented in the FTD research context, additional empirical research will be needed to determine the psychological and societal impacts of disclosure of OPBT results in genetic FTD and to make improvements to the counseling protocol to optimize support.

Biomedical Ethics session I (AFL-F-121)

Ashwin Budden

Title: Reciprocity and Responsible Innovation in Psychedelic Therapy: Lessons from an Ibogaine Partnership

Abstract: The rapid expansion of psychedelics research and wellness industry in the Global North raises ethical questions about collective harm and benefits for Global South actors. These include how to support distributive justice for traditional knowledge holders of psychedelics, and how to promote sustainable therapeutic innovations for converging mental health epidemics, namely PTSD, major depression and addiction). Ibogaine is a psychedelic metabolite in high demand in the Global North for its anti-addictive and psychotherapeutic properties and its commercial potential. However, biopiracy, poaching and an explosion of international psychedelic wellness tourism threaten iboga, the natural plant source of ibogaine, and the traditional Bwiti spiritual communities in the country of Gabon who are its stewards. Iboga is now called the "blood diamond" among natural psychedelics. A transnational access and benefit sharing (ABS) partnership emerged in 2020 between the government, an advocacy organization, and traditional communities in Gabon and a North American biotech and ibogaine-assisted therapy provider. The partnership is the world's first Nagoya Protocol-compliant mechanism aimed at promoting reciprocity, safeguarding traditional knowledge and bolstering sustainability for a natural psychedelic resource. The end of the partnership's strategic cycle in 2025 presents a timely opportunity to learn about how it is realizing its goals. Multi-sighted community-based participatory research carried out in Gabon and in Tijuana, Mexico investigates (1) the impacts --cultural, political and economic – of the ABS partnership and alignment of values and expectations among its stakeholders and (2) whether and how the biotech partner has complied with and advanced "sustainability" and "ethical" access, R&D and therapy delivery for iboga/ibogaine, and what the broader stakes are for the biotech industry. This case study of ABS in the iboga/ibogaine bio-culture contributes novel and learning to the global bioethics of reciprocity, equity and knowledge governance regarding bio-genetic and traditional resources. It aims to promote dialogue and action for policy and practice regarding responsible innovation in psychedelics.

Malene van Schaik

Title: Choosing Resilience: an innovation to put nurses in the lead

Abstract: Background and aim: Working in healthcare is becoming increasingly challenging due to staff shortages and increasing health care needs of an aging population. This challenge comes with an increased burden on nursing staff, which threatens their well-being and resilience, i.e their ability to navigate and bounce back from adversity and stressors in their work. Healthcare organizations have a responsibility to care for their care providers. However, a systematic approach to support nurse resilience at an organizational level is often missing. Additionally, the voices of nurses are rarely included in decision-making on how to support them, which we consider to be a form of epistemic injustice. Our research project therefore focuses on developing a method to put nurses in the lead in determining how they want to foster their resilience, and how they want to be supported by their organizations in navigating the burdens of their daily work. In line with our focus on nurse empowerment and control, we chose a participatory approach to our research, working closely together with nursing teams in co-creating a new intervention. Method: Participative co-creation study design with three nursing teams, in the Netherlands and a Community of Practice (CoP) with experts and envisioned end users of our innovation. A mixed methods approach was utilized to gain insight in the needs of the three nursing teams and their resilience at baseline (CD-RISC, n= 85). Our method, 'Choosing Resilience: Putting Nurses in the Lead', was developed and tested within three nursing settings (living labs): an ICU in an academic hospital, a nursing home and a hospice in the Netherlands. Through observations and interviews, the method was evaluated and further refined. Results: The method, 'Choosing Resilience', was iteratively developed and piloted by three nursing teams. The method includes six steps that guide nursing teams in identifying threats to their resilience, their needs for support, and which evidence-based interventions to try out and evaluate. Discussion: The method 'Choosing Resilience' is a promising innovation to support nursing teams in building resilience and being in control of the process and the choices for interventions and strategies that are made. A crucial condition for implementation and proper use of this method is the engagement and support of management and the allocation of resources to this aim within healthcare organizations.

Andrea Ferrario

Title: Patient Preference Predictors Revisited: Technically Feasible, Ethically Desirable, Yet Must Be Clinically Relevant

Abstract: Goal-concordant care—ensuring that medical treatments align with patient's values and preferences—is a key principle of patient-centered medicine, particularly in high-stakes, preference-sensitive decisions. However, determining preferences for incapacitated patients remains a persistent challenge. The absence of advance directives and the limitations of surrogate decision-making have led different authors to propose the use of algorithms—namely, a set of rules run by computer systems to predict an output of interest given input data—to estimate patient's most likely treatment preferences in case of their incapacitation. Since their proposal, these algorithms, originally called patient preference predictor—'PPP' or 'P3'—have risen to a broader technological competition—a 'race for Px'—where Px denotes increasingly personalized predictors, each reflecting a higher degree of predictive personalization. In fact, the underlying hypothesis driving the race is that expanding the granularity of data will yield more accurate approximations of patient's true, albeit often unknown, preferences. As a result, while early algorithms suggested population-based rules to predict category-level preferences, more advanced approaches suggest considering machine learning, even Large Language Models, incorporating large-scale data integration to compute individualized preferences. Our deliberate use of the verb 'suggest' underscores the theoretical nature of this endeavor. Despite extensive debate on the epistemic and ethical challenges posed by Px—spanning a broad and growing body of literature—no Px has been adopted in real-world clinical environments. The original promise of the patient preference predictor, i.e, to aid clinicians and surrogate decision-makers in making more informed treatment decisions, remains unfulfilled. We argue that this gap descends from the overgeneralization of the Px proposition, namely, its attempt to predict

treatment preferences across diverse clinical scenarios without being adapted to any specific context and medical condition. Thus, Px models can become clinically viable only if tailored to the constraints of specific clinicians and surrogates' interactions, which we explore through a neuro-intensive care use case within the context of incapacitation due to severe acute brain injury. While Px remains technically feasible and potentially ethically desirable, its success ultimately hinges on ensuring its clinical relevance.

Janine de Snoo-Trimp

Title: Fostering patient inclusion in clinical ethics support services – moving from research insights to innovative tools for practice.

Abstract: The perspective of patients is considered crucial in clinical ethics support services (CESS) focusing on patient cases, but from recent research we know that the patient is often not involved in CESS sessions such as Moral Case Deliberation (MCD). For several moral reasons, this paradox is increasingly considered as problematic. The aim of our participatory research was to better understand this paradox and to find directions to enable and stimulate patient involvement in MCD practice. We have collected insights and ideas from diverse stakeholders, including patients and patient representatives, through interviews. They expressed the need for better and preferably more direct representation of patients MCD. At the same time, they mentioned several concerns and challenges around patient participation, mainly considering equality, transparency, safety, the relationship between care-provider and care-receiver and the vulnerability of all participants. Research insights were translated into an ethics support tool and a masterclass for MCD facilitators. At the conference, we will share patients', care providers and facilitators' insights on when and how to prudently involve patients in MCD, and under which conditions. We developed an accessible tool for facilitators in which we provide recommendations for patient participation during the preparational phase, the session itself and the follow-up of MCD. We will also present the outline and content of our masterclass, which is intended to support MCD facilitators in (better) considering patient presence during MCDs. Since we met many challenges and potential barriers in carrying out this translational process, we would like to invite the audience to jointly reflect with us on this process as well. Lastly, we would like to discuss if and how our ethics support tool might be applicable to other CESS forms as well.

Fatih Bilgili

Title: Moral Injury and Moral Resilience among Healthcare Workers in the aftermath of 2023 Earthquakes in Türkiye: Navigating Systemic Challenges and Strengthening Moral Competencies

Abstract: The earthquakes of February 6, 2023, in Türkiye and Syria caused widespread destruction, resulting in over 50,000 deaths and more than 100,000 individuals severely affected. Beyond the public health crisis, healthcare workers (HCWs) faced extreme conditions, including resource shortages, overwhelming suffering, and the inability to save lives, which may have contributed to their moral injury. This phenomenon can erode core values, leading to guilt, helplessness, and distrust. Many HCWs left their jobs during and after the earthquakes. Türkiye's lack of preparedness and ineffective crisis management left them unequipped, exacerbating the impact. This study explores the moral injury experienced by HCWs who provided critical care during the earthquakes. We use a mixed-method study approach. First, the survey, composed of items questioning demographic information, Moral Injury Symptom Scale – Healthcare Professionals, and The Rushton Moral Resilience Scale, aims to determine the prevalence and correlation of moral injury and moral resilience within this population. Second, semi-structured interviews provide deeper insights into individual experiences. Initially, over 400 HCWs responded to the survey, and the sample size continues to grow. Additionally, a pilot study involving in-depth interviews offers further qualitative insights into the phenomenon of moral injury. In this study, we will present and discuss findings from both the survey and pilot qualitative study, focusing on collective resilience and systemic challenges in disaster response. We hypothesize a negative correlation between the frequency and individual scores of HCWs

experiencing moral injury and those demonstrating moral resilience. A general sense of distrust is evident among HCWs, particularly towards administrators and other teams, leading them to rely primarily on their own team members for support. Furthermore, widespread doubt about the possibility of systemic improvements discourages them from proposing structural reforms. Should these assumptions be validated, this study will provide a realistic perspective on the steps required to enhance HCWs' moral competences and moral resilience. Acknowledgment: This study is conducted as a part of DAYAN, a national project funded by TÜBİTAK, The Scientific and Technological Research Council of Türkiye. We would like to thank project adviser Dr. Fatma Zehra Öztek Çelebi and researcher Dr. Hüseyin Erkut Söğüt for their invaluable contributions.

Jürg C. Streuli

Title: Advanced Care Directives for Managing Loss of Decision-Making Capacity Ensuring Patient-Centered Care

Abstract: Advanced care directives (ACDs) offer vital guidance for medical decision-making when individuals are no longer able to communicate their preferences due to cognitive decline, severe illness, or an acute medical emergency. In these situations, healthcare providers and family members must rely on previously documented preferences to make informed decisions that align with the person's values and prior intentions. However, ACDs are often incomplete, ambiguous, or difficult to access in critical moments, which can lead to uncertainty, confusion, and ethical dilemmas. A practical solution to this issue is the introduction of structured counseling, paired with a newly developed, easy-to-use checklist tool. This tool is designed to assist individuals, in collaboration with their families and healthcare providers, in clearly identifying key medical and personal preferences. By doing so, it ensures that ACDs are not only medically relevant but also practically applicable when needed most. In addition, healthcare navigators (Gesundheitslotsinnen) can play a vital role in helping individuals develop these directives. They provide support in clarifying medical scenarios, ensuring that important aspects such as preferences for resuscitation, long-term care options, and symptom management are addressed in the directives. To further enhance their effectiveness in clinical settings, ACDs should be integrated into electronic patient records (EPRs). This would provide healthcare professionals with immediate access to the directives during both acute and long-term care, ensuring that treatment decisions are aligned with the individual's previously expressed wishes and alleviating the burden on family members and medical teams during critical decision-making moments. By combining structured counseling, practical tools, and digital accessibility, this approach can significantly improve the reliability and utility of ACDs, ultimately ensuring better alignment with patient preferences and more efficient healthcare delivery in Switzerland.

Poster Session I (Olivenhalle)

Dorian Accoe

Title: Polygenic embryo screening, donor selection and the ethics of neurodiversity

Abstract: Preimplantation genetic testing (PGT) brings innovations in human genetics and embryology together. The expansion of embryo screening is expected to include polygenic risk scores (i.e. polygenic embryo screening (PES) or PGT-P), which is already offered by some private companies. These scores provide probabilistic information about the development of complex, polygenic conditions such as certain cancers, diabetes and schizophrenia, and – at least in theory – could also be used to identify higher probabilities of autism. In practice, a 'low-tech' version already exists for third-party reproduction: candidate donors with a family history of autism are excluded from donation and when a donor-conceived child is diagnosed with autism, the gametes of that donor are no longer used in medically assisted reproduction. While the literature on PES for autism has so far mainly focused on its clinical validity and utility (e.g. highlighting its modest predictive value), bioethical research on the desirability of embryo/donor

selection against autism is limited. Drawing on insights from neurodiversity activists and crip scholars, this presentation – firstly – challenges arguments of proponents of selecting against autism, and – secondly – articulates normative concerns against such practices. First, claims in favor of embryo/donor selection highlight that autistic persons (or their families) report lower wellbeing and higher rates of 'comorbidity'. However, wellbeing metrics are typically based on neurotypical standards and may fail to capture the adaptive strengths and distinct values within neurominorities. Lower wellbeing can also reflect societal non-accommodation rather than an intrinsic deficit. Moreover, if the aim is to mitigate 'comorbidities' (e.g. depression), it would be more effective to target those predispositions directly, rather than using autism as a proxy. Second, selection against autism reinforces stigma and negative stereotypes, and risks endorsing a form of eugenics by framing (neurological) differences as deficits. Such practices uphold an outdated hierarchy within neurotypes, raising ethical concerns regarding autonomy, justice and broader societal implications of defining 'normalcy'. It is concluded that selecting against neurodivergence casts neurological differences as pathological, genetic deficiencies, and underscores the need for normative reflections on how such differences are valued and accommodated in society.

Remo Schraner

Title: Patient and Public Involvement in Youth Mental Health Research: Conceptualization and Implementation of a Youth Council

Abstract: Patient and Public Involvement (PPI) ensures research is both relevant and ethically responsible. In youth mental health research, collaborating with young people helps address key challenges such as limited help-seeking, high care gap, and high dropout rates. It further enhances research relevance, ethical integrity, and public trust while promoting transparency and real-world impact. Challenges of PPI are the required resources and a decelerated research process. Given the ethical responsibility inherent in researching youth mental health and the clear potential for PPI to enhance the relevance and impact of our work, the potential advantages outweigh the challenges. This contribution will outline how PPI can be integrated into research, with a focus on youth mental health research, using the example of a Swiss research group, and share initial evaluation insights. Based on the Montreal Model, which emphasizes active collaboration between researchers and the public, we are establishing a Youth Council for Public and Patient Involvement in our division. In line with this model, both the involved young individuals and researchers are trained to ensure that young people's voices are not only heard but actively shape the research process. This council consists of 4 to 8 adolescents (aged 14–18) who collaborate with researchers on aspects such as developing research questions, study design, recruitment, data interpretation, and dissemination of results. At EACME, this contribution will outline best practices to strengthen PPI, emphasizing interdisciplinary collaboration (i.e., advisory board including international experts, youth organizations, and institutions) and training of researchers to collaborate effectively with adolescents while addressing hierarchies and participation barriers. Furthermore, first evaluation results/current projects worked on in the youth council will be presented. By embedding PPI into youth mental health research, this project contributes to socially responsible and relevant research. Involving young individuals as equal partners fosters ethically sound, transparent, and patient-centered research, leading to more sustainable and equitable outcomes of youth mental health research.

Marijn van Es

Title: Remote monitoring for Parkinson's disease with wearable sensors: 'soft' impacts on users and their daily lives

Abstract: In-clinic evaluations of the progression of Parkinson's disease may not always be representative of how someone functions in daily life. Sensor-based technologies enable continuous monitoring in real life situations. Wearable sensors may capture how people function at home, promising to provide more realistic

test results than current clinical assessment, and expected to be useful as endpoints in clinical trials, and to support personalized healthcare and patient self-management. Whether remote monitoring will be acceptable to users and society at large depends, among other things, on the impact of remote monitoring on users and their daily lives. Apart from the intended effects, remote monitoring technologies may have unforeseen impacts. We are particularly interested in the so-called ‘soft impacts’, a concept coined by Tsjalling Swierstra. Soft impacts are subjective and cannot be quantified, and refer to the way in which technologies shape our behavior, relationships, norms, values and expectations. By contrast, ‘hard impacts’ are considered to be quantifiable and concrete and typically receive more attention. Soft impacts of technology often fly under the radar and are usually considered too ‘soft’ to be taken seriously. In this study, we conduct semi-structured interviews with persons with Parkinson’s disease and their relatives to explore (1) how persons with Parkinson’s disease experience remote monitoring, and (2) what soft impacts remote monitoring has on these persons and their daily lives. The informants are participants of three different clinical studies for which remote monitoring with wearable sensors and smartphone apps is a key component. In a preliminary analysis we found, among other things, that experiences of users with remote monitoring go beyond experiences with (using) the device alone. Regarding impacts, some users hide the wearable sensor or steer conversations to keep attention away from the device. For others, remote monitoring reminds them of their disease, which does not necessarily have a negative (and sometimes even positive) effect. Some users adjust habits, for instance to meet a certain step goal. This presentation will (1) shed light on possible soft impacts of remote monitoring for Parkinson’s disease, and (2) address the questions of what these soft impacts mean for the (un)desirability of this technology and how this contributes to responsible research and innovation.

Julián Riaño Moreno

Title: Anthropotechnic Vulnerability: Rethinking the Physician-Patient Relationship in the Age of Artificial Intelligence

Abstract: Artificial Intelligence (AI), as an autonomous and highly efficient technology, promises to optimize processes in healthcare, profoundly transforming the physician-patient relationship (PPR). Integrating AI positions physicians and patients within a complex digital-industrial system that prioritizes efficiency, accuracy, and commercial gain over traditional PPR values such as honesty, trust, and confidentiality. This shift creates new vulnerabilities, traditionally overlooked or narrowly addressed through technical risk-management approaches. Recognizing these limitations, this study employs a hermeneutic methodology to analyze recent ethical perspectives on vulnerability and technology (Henk ten Have’s global bioethics, Corine Pelluchon’s ethics of care, and Mark Coeckelbergh’s ethics of technology). Our central premise is that definitions of vulnerability depend intrinsically on authors’ conceptualizations of technology. Accordingly, we propose an integrative "anthropotechnic vulnerability" model informed by post-phenomenology, interaction theory, sociotechnical systems theory, Sloterdijk's anthropotechnics, and moral imagination. This novel approach moves beyond static understandings of vulnerability, capturing its dynamic nature shaped by both human and technological interactions. Finally, we introduce the "STS model of the PPR," offering a comprehensive analytical framework to ethically examine how AI redefines medical interactions, vulnerability, and healthcare justice in the digital era.

Suzanne Metselaar

Title: Innovating Ethics Support for Everyday Ethics: The CURA project (2017-2025)

Abstract: Background: Within an increasingly difficult healthcare landscape, care providers are confronted with moral challenges on a daily basis. If not sufficiently equipped, empowered and supported in dealing with these challenges, their well-being and the quality of care are under threat. It is therefore of the essence that, complementary to existing forms of ethics support, which often focus on larger and more exceptional

moral dilemmas in the presence of a clinical ethicist, there are also low-threshold interventions in place to support care providers in dealing with ‘everyday ethics’ themselves. This requires innovation of clinical ethics support. We will present the CURA project (2017-2025) as an example. Aim: To discuss the importance of innovating ethics support in order to empower and support healthcare providers in dealing with ‘everyday ethics’ themselves. We argue that this innovation should take place in close collaboration with care providers in order to fully attune to their wishes, needs and professional contexts. We use the CURA project to illustrate this. Methods: After using a participatory development design to co-create CURA together with care providers and other stakeholders, we tested its feasibility among nurses (n=123), and studied the effects of CURA on the moral resilience and moral competences of care providers (n=82) with two validated scales (RMRS and EURO-MCD 2.0). Our implementation study focused on facilitators, barriers and strategies for implementing CURA in 13 healthcare facilities. Results: CURA is a low-threshold clinical ethics support instrument that enables healthcare providers to reflect on the moral challenges they encounter in daily practice themselves. CURA is found to be effective in strengthening moral competences and moral resilience, and to be feasible to use in everyday practice. We have insight into the strategies for the implementation of CURA in diverse healthcare settings, and developed a training for ‘CURA ambassadors’, i.e. care providers who introduce, facilitate and implement CURA in their organization. Today, CURA is widely used in healthcare and education in the Netherlands.

Jana Wegehöft

Title: Ethical considerations in communication practices within a local group-based dementia prevention programme: Social and ethical challenges and potential modifications

Abstract: Research in recent years has focused on the prevention of dementia. Due to limited pharmaceutical options, as well as advances in diagnostics and the identification of risk factors, preventive measures have become more central. Recommendations range from lifestyle adjustments to (digital) memory games and participation in prevention courses that provide knowledge and practical measures. While these are seen as an opportunity for risk reduction from a medical and health policy perspective, there is also criticism of their limited effectiveness and the associated expectations and fears. My qualitative study, which is situated at the intersection of cultural anthropology and medical ethics, examines how primary dementia prevention is addressed in a local group programme. Based on nine semi-structured interviews and eight participatory observations, it becomes evident that dementia is not explicitly mentioned in the courses attended. Rather, the participants perceive the courses as a general activation programme for older people. The course instructors aim to promote positive health effects, but avoid directly addressing the topic of dementia because it is associated with fear and stigma, potentially deterring participation. This avoidance contributes to the further tabooing of dementia and makes it difficult to deal with dementia and its prevention options in a meaningful way. Based on medical ethics principles, suggestions were developed to improve communication about dementia in the courses and to encourage the participation of older people in dementia prevention courses. These recommendations aim to strengthen the autonomy, freedom of choice, and practice-oriented actions of the participants, while taking their fears and uncertainties into account. The suggestions, based on current course structures and the participants' desire for a greater focus on dementia, include transparent and respectful information delivery. This approach should empower participants to make informed decisions and take responsibility for their health. My analysis also highlights the need for a more in-depth examination of the relationships between dementia stigmatization and prevention in order to develop alternative concepts to mitigate the social impact. The developed drafts for adapted dementia communication in the local course offer a starting point for further ethically informed concepts that address and engage people in a context-sensitive way.

Philippe Mathys

Title: Reasons for allowing new plant breeding technologies from a planetary health perspective

Abstract: New Plant Breeding Technologies (NPBTs), including marker-assisted selection, genomic selection, and CRISPR-Cas9 gene editing, offer more efficient and flexible innovations in agriculture than traditional methods. They are used, for instance, to enhance pest and disease resistance, abiotic stress tolerance, product quality, and crop diversity. NPBTs are expected to make food production more sustainable, environmentally friendly, and contribute to global food security, public health, and sustainability. However, genetically modified food traditionally causes polarizing political and public debates. While in some regions, including the United States, they symbolize neoliberalism, the European region has regulated their use more strictly, following a precautionary approach. NGOs have raised concerns about genetically modified food related to potential risks to biodiversity and economic motives dominating the use of NPBTs in the food market. European plant scientists, by contrast, have criticized the strict regulations of NPBTs, emphasizing their safety and potential to revolutionize and democratize the food market. In this contribution, I will present findings from a systematic review of reasons that maps the full spectrum of reasons for and against the use of NPBTs in the scholarly debate. I will discuss the implications of these findings through a planetary health ethics perspective that sees the health of human and non-human animals and the environment as inherently interconnected and assesses the moral status of these interconnections.

Jeremy Power

Title: Getting personal: Ethical issues of personalised medicine in chronic kidney disease

Abstract: Background: Kidney disease, including chronic kidney disease (CKD), affects more than 850 million people worldwide. Yet, CKD remains largely overlooked by public health policies. In response to the public health burden of CKD, the PICKED (Personalised Medicine in Chronic Kidney Disease) project aims to implement personalised medicine (PM) practices in CKD through early disease detection, monitoring of disease progression, and personalised treatment, including dialysis. As innovative personalised solutions for CKD are developed, it is essential to integrate ethical reflection throughout their design, implementation, and use. This is particularly important because PM could fundamentally change how medicine is delivered in clinical settings through tools such as whole-genome sequencing and artificial intelligence. Therefore, this project aims to assess the ethical, legal, and social issues associated with the development and implementation of PM practices for CKD. Methods: This study will analyse three specific applications of PM in CKD: the clinical use of peptides for disease diagnosis and prognosis, the optimisation of dialysis through disease biomarkers, and the impact of CKD diagnosis—particularly prenatal diagnosis—on paediatric patients and their families. The study will include a content analysis of semi-structured interviews with professionals (nephrologists, genetic counsellors, paediatricians, bioethicists, and researchers) as well as patients within EU patient associations (such as the European Kidney Patients' Federation). Results: This study will develop an ethical, legal, and social framework based on the analysis of these three PM applications to better prepare them for clinical use. We will examine key issues in PM, including data protection and privacy, discrimination, and equitable access to treatment. A significant concern is that PM promises to enhance patient empowerment by offering tailored diagnoses and treatments and increasing patient participation in decision-making. While this shift can be beneficial for many, it may also place greater responsibility on patients for managing their own disease. In the context of the complicated prognosis and treatment of CKD, this study aims to produce recommendations so that patient and clinician preferences are better understood. Conclusion: This study will provide an interdisciplinary perspective to the PICKED project, contributing to the development of much-needed solutions for CKD.

Jona Simon Carlet

Title: A practice example in integrating Patient and Public Involvement in psychiatric research: Ethical reflections and practical considerations

Abstract: The integration of patients, relatives, and lay stakeholders as co-researchers has gained increasing prominence in health research over the last decades. This approach - often called framework of Patient and Public Involvement and Engagement (PPIE) - aligns with the United Nations' Convention on the Rights of Persons with Disabilities, fostering participation and contributing to the democratisation of knowledge. However, realising meaningful PPIE presents significant ethical and practical challenges, particularly in relation to structural discrimination and epistemic (in)justice. This poster outlines the ongoing efforts to establish PPIE support structures at the University Hospital of Psychiatry in Zurich, Switzerland, a major psychiatric research institution. Beginning with a multi-stakeholder workshop in 2022, the initiative has since evolved towards the development of a PPIE consultation structure for research projects at the institution. The aim of the consultation is to enable clinical researchers to involve co-researchers, e.g. by teaching them the PPIE framework, advising them on how to develop a PPIE research design and building contacts and network with stakeholders. In this way, clinical researchers learn how to productively incorporate the knowledge perspectives of co-researchers into the scientific process and empower all stakeholders to use PPIE. The poster details the concrete steps taken to institutionalise PPIE and also addresses the ethical and structural barriers encountered in this process. By highlighting both challenges and potential solutions, this presentation aims not only to promote PPIE as a research framework and to provide insights for researchers wishing to implement PPIE in their own institutions, but also to reflect on the ethical challenges of implementing PPIE.

Parallel Sessions II

Ethics at the Crossroads of Reproduction, Parenthood, and Care (AFL-E-015)

Nathalie Bettina Neeser

Title: "Age independent, but person dependent": A Swiss interview-based study on the meaning of good parenthood at an advanced parental age

Abstract: Child welfare is one of the most important topics when it comes to parenting competence and the definition of good parenthood. This is widely discussed, especially in the context of treatment considerations for medically assisted reproduction (MAR) for patients of Advanced Parental Age (APA, here defined as 40 years and older). The aim of this study is to contribute to the exploration of how different stakeholders in this context envision the concept of good parenthood. An explorative semi-structured interview study was conducted with a total of 15 healthcare providers, 12 aspiring APA-parents, 21 APA-parents and 20 adult offspring of APA-parents. After thematic analysis, results show that although the connecting focal point among participant groups is reproductive age, participants consistently emphasized that APA is not a determining factor to define a "good" parent. Instead, we identified three themes representing participants' views on this topic: (i) the difficulties in defining good parenthood; (ii) the family structure and context as inherent to parenting quality; and (iii) good parents as conscious adapters. Participants expressed their views that good parenthood depends on the personality of the parent, rather than on one single characteristic of a parent, such as age. Our results challenge the focus on a singular parental characteristic in safeguarding the welfare of future children and therefore also the role currently attributed to parental age in decisions about access to MAR.

Leonie Abstein

Title: Ethical Reflections on Assisted Reproductive Technology and Parenthood as a “Form of Life”

Abstract: The responsible integration of innovations into medical practice requires a comprehensive and nuanced ethical assessment. This also concerns advancements in assisted reproductive technology (ART). This contribution uncovers ethically relevant dissonances in the scientific and public discourse on ART and proposes a way to foster a more nuanced understanding of its normative implications.Dissonances in the ethical discourse on ART can be identified on a content-wise and a methodological level. Content-wise, there is a predominant focus on the assessment of the application of reproductive technologies, like in vitro fertilisation, cryopreservation of gametes and embryos, or uterus transplantation, while their normative implications are often ignored. This is associated with a neglect of underlying issues such as intended parenthood and the unfulfilled desire to have a child, which are referred to as the actual motives for research and application of ART. Methodologically, deontological and naturalistic approaches dominate, whereas approaches based on the ethics of goods are underrepresented. Both dissonances are related to a contemporary naturalistic-mechanistic conception of the human being prevailing in medical practice, which disregards anthropological notions of human vulnerability and the limits of control. Overestimating the possibilities of ART due to dysfunctional notions of feasibility can, for example, promote suffering, misunderstandings and pathogenic treatment practices. This article examines how ART transforms societal conceptions and structures of parenthood, family, reproductive autonomy, and the unfulfilled desire to have a child. As a theoretical framework for the analysis I will utilize, Rahel Jaeggi’s concept of "forms of life", which she understands as normative structures of social practices. Based on her concept I will deepen the analysis by referring to the ethical approach to goods. By integrating philosophical, theological, and social science perspectives, this contribution aims to foster a more differentiated understanding of the normative implications of ART on an individual and structural level. In this way, key insights are developed for responsible research as well as for assessing the opportunities and limitations of ART in practice.

Ilvie Prince

Title: The Paradox of "Optimistic Counseling" - Debate and Disagreement Around Contraceptive Side Effects

Abstract: Nearly half of all pregnancies, 121 million worldwide each year, are unintended. This is true not only in developing or underserved areas, but also in countries like the United States. Campaigns by the World Health Organization and family planning NGOs seek to educate about the effectiveness and promote the use of highly effective measures such as hormonal contraceptives, ideally intra uterine devices. Despite these efforts, the number of women using highly effective contraceptives such as contraceptive pills have been declining for years. One of the main reasons for discontinuation of hormonal contraception is the experience of adverse effects, especially those described in the medical literature, if described at all, as mild or minor. To improve patient adherence and reduce the risk of unintended pregnancy, clinical guidelines encourage clinicians to pay more attention to their patients' values and preferences when providing contraceptive advice. Despite this emphasis on good communication and openness, there is a striking contrast in a common recommendation regarding information on minor adverse symptoms where so-called 'optimistic counselling' is advocated. Optimistic counselling involves little or no discussion of potential side effects, and reassurance to users who come in with complaints that they are temporary or not related to the intervention. Social science research shows that such strategies are used in both the global North and the global South and have a lasting negative impact on users' trust in the doctor-patient relationship. While strategies such as optimistic counseling are criticized in the social science and philosophical literature as paternalistic and explained by ingrained sexist double standards, medical researchers and clinicians defend optimistic counseling as well founded. In my talk, I will discuss the roots of this conflict and how optimistic counseling is grounded in accepted professional, ethical, and epistemic norms. It is true that optimistic counseling seems to be justified by certain aspects of professional obligations, such as preventing disease, following the principle of nonmaleficience, and using the (supposedly) best evidence. However, a deeper analysis reveals that these institutionalized norms and conventions lead to paradoxical results in the case of

contraceptive counseling, creating agnotological barriers and systematically impeding an informed risk-benefit assessment by contraceptive users.

Andrea Martani

Title: Too late to become parents? An empirical-bioethics study on fertility patients', clinicians and adult children on parenthood timing

Abstract: New technologies and innovation in the field of Medically Assisted Reproduction (MAR) has expanded the reproductive choices of many people. This had a profound impact on core ethical principles in this field, such as on the scope of reproductive autonomy. Indeed, the fact that technology and innovation now permit many more people to have children has also raised questions on whether any limits on the use of these technologies should be imposed. One of the most important doubts regarding the ethical use of new MAR technologies concerns older parents. Modern fertility medicine allows patients to try and conceive far beyond the 'normal' reproductive age, which has raised doubts on whether this should be considered ethically problematic. Some ethicists call into question whether older age diminishes the capacity to parent, and others caution against the risks for the welfare of the child and the pregnant person in case of using MAR late in life. As a result, many states have also set explicit parental age limits in their laws on MAR access, thus forbidding older parents to conceive through MAR. However, many doubts remain on whether such limits are justified, or if there are indeed any valid ethical arguments to argue that some people are simply too old to have a child. Whilst the ethical literature on this topic is mainly theoretical, in this presentation we will report the results of an empirical bioethics project where we involved MAR patients, clinicians and adult children from older parents to reflect on the ethics of age limits for parenting. We conducted semi-structured interviews 68 such stakeholders, where – using elicitation techniques – we motivated them to discuss parental age, parenthood capacity and access to MAR. We then used the method of reflective equilibrium to integrate their moral intuitions on appropriate age for parenting within a broader ethical reflection on whether there should be any age limits for access to MAR from an ethical perspective. In this talk, we will both present the results of our study, but also reflect on the challenges of using empirical bioethics methodologies to integrate patients' and stakeholders' views and values into bioethics research.

AI in Healthcare (AFL-E-011)

Zara Malgir

Title: Facing the Algorithm: The Urgent Need to Advance Patient Automation Literacy in the Age of Medical AI

Abstract: We are living through a profound shift in how people engage with technology - one where artificial intelligence (AI) is no longer confined to research labs or expert domains, but is increasingly woven into the fabric of everyday life. Nowhere is this transformation more consequential than in healthcare. As AI-driven systems become routine tools for diagnosing, advising, and even treating patients, the line between expert and layperson is rapidly blurring. While automation literacy efforts have traditionally focused on equipping healthcare professionals to work alongside AI, this is no longer enough. Patients themselves are becoming direct users of medical AI, turning to chatbots, symptom checkers, and virtual assistants to manage their health. With over 120 medically approved AI-powered chatbots currently deployed, we must now confront a critical question: How prepared is the public to navigate this new healthcare landscape? This paper explores the urgent need to extend automation literacy beyond the clinical setting and into the public sphere. It discusses what meaningful medical AI literacy should look like for patients, where such knowledge can be cultivated - from schools to public health campaigns - and how society might incentivize lifelong learning in this space. In doing so, it unpacks the ethical stakes of leaving patients under-informed in an AI-driven world, particularly in a time when health decisions are increasingly mediated by opaque technologies.

Automation literacy, especially in medical contexts, is no longer a luxury or a niche interest - it is a societal imperative for equity, agency, and trust in the future of healthcare.

Eike Buhr

Title: Trust and Artificial Intelligence in the Doctor-Patient-Relationship: epistemological preconditions and reliability gaps

Abstract: The use of artificial intelligence (AI) in healthcare is increasing, encompassing various fields of medical applications. A central concern here is trust or trustworthiness, as demonstrated by the framework of the High-Level Expert Group on Trustworthy AI. This is particularly significant in healthcare, where trust plays a foundational role in the doctor-patient relationship. While some argue that AI cannot be trusted, others advocate for concepts like e-trust. However, there remains a gap in understanding how trust varies across different AI applications. For example, trusting AI for melanoma detection differs fundamentally from trusting AI-based chatbots. We argue that a one-size-fits-all concept of trust oversimplifies the issue, neglecting the contextual nature of trust and the distinct epistemic stances that shape trusting relationships between doctor and patient in different human-machine interactions. Disregarding these aspects risks overlooking potential conflict between concepts of trustworthy AI and the fiduciary doctor-patient relationship. In our presentation, we map epistemic stances across different modes of human-machine interaction and explore the unique ethical issues they raise. To this end, we first sketch different conceptions of trust and show how trust differs from reliance. In a next step, we map different modes of basic human-machine interactions. Finally, we show what kind of epistemic stances are involved in applying trust to different modes of human-machine interaction and to what extent these bear ethical implications. In scenarios involving more advanced AI, we identify reliability gaps, where asserting the reliability of an AI-system comes into conflict with asserting the trustworthiness of the doctor. Against this backdrop, we argue for a comprehensive understanding of trust, considering both technological and human elements and providing a framework for understanding trust in AI within healthcare contexts.

Lukas Kiefer

Title: “Trust me, I am a data fiduciary”

Abstract: Background: Health data and data sharing are essential for innovations in the health care sector – e.g. for training AI tools. Empirical studies indicate that trust plays a key role in data sharing. However, due to lack of trust in the data sharing process or institutions and persons involved, data subjects refuse to share data for research purposes. Hope is that data fiduciaries as intermediaries between data subjects and data users will increase trust and thus foster data sharing – provided that they are as trustworthy as their name “data fiduciary” or “data trust” promises.Ethical Challenges: A fiduciary relationship is characterized by the following attributes: A fiduciary (data fiduciary) is entrusted with discretion over interests of a beneficiary (data subject), which he uses for the benefit of the latter. Such relationships are intended to express a special trust or trustworthiness. In our project we analyze this underlying trust structure and the question whether existing data fiduciary models sufficiently reflect the corresponding requirements. Approach and Discussion: We argue that to establish well-grounded trust in a data fiduciary two conditions must be met: Firstly, the fiduciary must be trustworthy. Secondly, data subjects need to be convinced of the trustworthiness, as – due to the discretion of the fiduciary – a certain amount of initial trust is required to get the fiduciary relationship started. The first condition can be met with the ethical-legal framework for data fiduciaries grounded in the characteristics and duties of a fiduciary relationship, e.g. the duty to share data only if it is in line with the interests of the data subject. For this, the data subject’s interests must be evaluated (e.g. sharing data to support medical research). The second condition requires considering the individual reasons for trust as these are dependent on the individuals themselves. In this regard public reputation of institutions, transparency and external reviews (e.g. certifications) can be important factors.

Empirical studies must be considered here. Conclusion: Data fiduciaries can only fulfill the hope to increase trust if both conditions are met: Firstly, trustworthiness based on the ethical-legal framework. Secondly, initial trust of the data subject to get the relationship started. A first examination of existing data fiduciary models shows that some models do not sufficiently reflect these requirements and misuse the name “fiduciary”.

Jamie Webb

Title: The ethics of selective deployment of AI in an infectious disease outbreak

Abstract: Vandersluis & Savulescu (2024) have argued in favour, in some particular circumstances, of the selective deployment of AI technologies where algorithmic performance levels is materially worse for subgroups. These include contexts where the benefits to the majority group of AI deployment are sufficiently high, and where non-algorithmic solutions can be provided to relevant subgroups whilst steps are taken to redress the epistemic causes of less effective model performance. The case-studies they provide to justify this claim focus on the use of AI in routine clinical care. This presentation considers whether selective deployment can be ethically justified or practically feasible if AI is used during an infectious disease outbreak. This presentation will evaluate the applicability of Vandersluis & Savulescu’s arguments for selective deployment considering the differences between clinical and public health ethics. These include the latter’s focus on populations rather than the individual, the different balance between equity and utility, the different ethical paradigms for treatment versus prevention, and the importance of solidarity as an ethical value. It will conclude by making recommendations for the possible deployment of AI technologies in an infectious disease outbreak.

Matt James

Title: In the Face of IT: Ethical implications posed by the biometrics ‘gaze’

Abstract: Biometric technology has rapidly evolved in recent years pervading many areas of public life, not least in the domain of healthcare. Biometrics, literally meaning “life measurement”, can be defined as the science of establishing and verifying the identity of an individual based on their physical, chemical or behavioural attributes (Jain et al., 2007). By leveraging unique biological traits such as fingerprints, facial recognition, and iris scans, biometrics enhances accuracy in patient matching, reduces medical errors, and secures sensitive health information. The collection, storage, and use of such data could offer many opportunities to make healthcare more personalised by enhancing the quality of healthcare by reducing medical errors and improving capacity to react to medical emergencies (Mordini & Ottolini, 2007). Applications extend to telemedicine, remote patient monitoring, and self-service healthcare systems, improving efficiency and accessibility. The adoption of biometrics raises ethical challenges related to privacy, informed consent, data security, and potential biases in biometric systems. Foucault’s concept of the medical gaze, introduced in The Birth of the Clinic (1963), provides a critical lens through which to analyze the implications of biometrics and the scope for an extension of the medical gaze. This paper will explore the extent to which biometric technologies may help to objectify patients by reducing them to data points—unique identifiers detached from their personal identities. Drawing upon experience serving on the UK Government Home Office’s biometrics ethics group, the paper will explore how biometric technologies amplify this dynamic by embedding surveillance capabilities into healthcare systems, raising questions about who controls this data and how it is used (Biometrics Institute 2025). What could be framed as an aid to greater personalisation and patient empowerment, could become a form of intense surveillance, redrawing the boundaries between health, illness and disease and subjecting the individual to new forms of self-surveillance, that may disproportionately affect marginalized populations (Kavanagh et al 2018). Addressing these ethical implications is crucial to ensure that biometric technologies in healthcare respects individual rights, promotes trust, and maintains the inherently human experience which is crucial to the practice of medicine and healthcare.

Methods in Ethics Research (AFL-E-022)

Fifianne Rigter

Title: Exploring graphic novels in ethics education: key themes and research gaps

Abstract: Graphic novels, with their blend of visual and textual storytelling, have emerged as promising tools to elucidate complex ethical concepts. Their potential to enhance engagement, critical thinking, and ethical reasoning makes them attractive for ethics education. This scoping review systematically maps the existing literature on the use of graphic novels—and similar media—in teaching ethics, with the aim of identifying key themes and research gaps to inform future educational modules, including one focused on pandemic-related bioethical concepts. We performed a comprehensive search using a structured query that combined terms related to graphic novels, education, and ethics. A rigorous two-stage screening process (title/abstract followed by full-text review) resulted in 26 studies being included. The selected studies were analyzed through thematic analysis to extract insights on the design, implementation, pedagogical goals, and evaluation strategies of graphic novel-based educational interventions. The literature revealed considerable diversity in the approaches to selecting or designing graphic novels for ethics education. Some studies utilized pre-existing works while others developed new graphic novels tailored to specific educational contexts. Common themes included fostering critical thinking and facilitating ethical reasoning. However, only a subset of studies explicitly defined their pedagogical approaches, learning objectives, or ethical domains, and many lacked robust interactive elements and systematic feedback mechanisms. We conclude that graphic novels represent a valuable, engaging medium for ethics education, yet optimal learning outcomes require clearly defined ethical domains and pedagogical goals, as well as the integration of interactive components and consistent evaluation strategies. These insights are instrumental in shaping future teaching modules, particularly for addressing bioethical challenges highlighted during pandemics.

Annina Gähwiler

Title: Co-Creation in Digital Health – Introducing a Novel Process Model to Initiate the Necessary Mindset Shift

Abstract: The objective of this exploratory work is to shed light on the concept of co-creation in the context of digital health. It adds a critical perspective to discuss the potential and limitations of co-creation. It emphasizes that a shift in mindset is necessary to establish and further promote co-creation. To facilitate this, a novel process model is proposed. Involving patients and the public in the development process of digital health solutions is increasingly becoming standard practice. Co-creation is a comprehensive approach to participation and is characterized by involving all stakeholders on an equal contribution of knowledge throughout the overall process. It is thought to increase adherence and effectiveness by empowering the end-users to co-develop digital health outcomes tailored to their circumstances and thus achieve positive societal changes. The literature states that limitations of co-creation are the lack of a standard process, of evidence of best practice for meaningful co-creation and of measurable outcome indicators. However, there is a need to close a much more profound knowledge gap: A co-creation process is not predictable and non-linear. It resembles an unexplored path. An open outcome endeavor as such is associated with risks in terms of extra cost, effort and time. A mindset shift is required to embrace this uncertainty and to familiarize oneself with the work in progress. Co-creation as a context-sensitive, collaborative and socially engaged interaction demands openness as it blurs the boundaries between science and society. This is precisely the unknown field in which questions, methods and solutions can emerge that serve a broader goal. To navigate the challenging path toward meaningful co-creation, a new process model is proposed, structured around three key phases. At its core, the model focuses on creating meaning and establishing a common foundation as the overarching goal of co-creation. Building on this, it defines the framework and creates a safe space that facilitates knowledge transfer while incorporating mechanisms of transdisciplinary collaboration. In practice, co-creation methods are applied to iteratively develop prototypes, foster continuous learning and build new competencies. The emphasis remains on

ongoing adaptation, extending beyond the initial implementation phase. This novel perspective of co-creation is aimed to inspire practical case studies guided by an overarching goal and embracing non-linear processes.

Alexander Kremling

Title: Chances and challenges. Implications of integrating participatory research into ethics research

Abstract: There is a growing trend (and demand) to integrate participatory research into research practice which also affects and includes ethics projects. This is typically justified by a mix of ethical and pragmatic arguments but often based on general considerations and less on examples from research practices. We integrated patient and public participation methods into a medical ethics subproject of the iSedPall project in which we developed and piloted ethics support material for sedation in palliative care over the course of 3 ½ years. We established a local participatory research group (PRG) and offered several methods of participation, sometimes focussing more on transparency (informing; providing background information; 'data audit' regarding systematic literature search, invitation to meetings and workshops), sometimes on indirect participation (e.g. literature and case discussions), sometimes direct participation (e.g. working on drafts or decision about prioritization of work). The group influenced the final results of the project in both direct an indirect ways. The iSedPall ethics process provides several examples for ethical aspects of participation that seem to be, so far, poorly reflected in the general literature about participation. These examples can contribute to general conclusions about participation in ethics and might improve future participation decisions: (a) Some patient populations cannot participate which increases the problem of representativeness and strength of ethical 'participatory conclusions'. (b) A participation process is highly time-consuming with working time of the researchers itself being a limited resource. (c) A PRG might be manipulable towards one or the other ethical position concerning highly controversial questions (such as, in our case, proactive informing about physician assisted suicide or informing about limitations of palliative home care). A PRG can be an argumentative tool in the hands of researchers since it increases the perceived weight of the ethicists opinion in a debate ('The public thinks so too') which in turn requires an ethical 'use' of a PRG. These challenges require pre-emptive measures, caution and maybe also some critical discussion independent of the comprehensible yet sometime a bit too general assumption that participation per se is a good and valuable thing.

Tessa van Rijssel

Title: The role of social value in data-intensive health research

Abstract: Data-intensive health research complicates traditional ethical requirements for informed consent, due to among others the extensive amount of participants and data points, open-ended nature of research questions, and repeated usage of data. In order to still enable data-intensive health research, there is a move towards other – generally lower – standards for consent such as opt-out systems, in current developments such as the European Health Data Space (EHDS). This is often premised on the public good or social value that data-intensive health research will provide through enabling scientific research and innovation. Traditionally, social value functions both as a fundamental requirement for research, as well as a ground to justify individual risk in research ethics. However, ongoing debates surrounding data-intensive health research suggest that social value can also be used to justify lower standards of consent. Social value seems to obtain an additional and distinct role. This raises questions on the role of social value in research ethics and evaluations on the acceptability of research. In this paper, we examine three possible roles of the social value requirement: (i) to prevent research waste and set research priorities; (ii) to justify exposing research participants to risk; and (iii) to lower standards for consent. Subsequently, we discuss the consequences of these various roles for the conceptualization of social value. We conclude that the way social value is invoked – whether to justify research, justify risks, or justify lower consent standards – should

shape how we define and establish the requirements for social value itself, including who should or could have a say in defining it.

Clemence Van Ginneken

Title: The art of (health)care: responsible innovation through responsible imagination

Abstract: In light of establishing inter- and transdisciplinary research in medicine, the domain of Medical Humanities (MHs) has gained traction in the last forty years. In this tradition, healthcare research is increasingly becoming receptive to types of input other than those originating from biomedical sources sensu stricto. Interestingly, among these 'non-biomedical' inputs, systematised findings from mainly academic disciplines prevail – such as psychology, anthropology, history, etc. – indicating that a scientific methodology seemingly remains the overall requirement. We argue that such a narrow conception of MHs falls short on ethical grounds, which simultaneously propels towards calling for an introduction of art, aesthetic practices and imagination into medicine and healthcare. Our argument starts from the premise that there is good reason for including insights from the 'humanities disciplines' mentioned above, for they can bring into view perspectives or experiences that are ignored or neglected, all the while they are relevant for understandings of health. We then continue that, likewise, there is no a priori reason why different art forms, for instance, could not play a similar enriching role. To substantiate this, we build on Margaret Urban Walker's argument for a critical and naturalized 'empirical enrichment' of moral contexts. Allowing artistic expression as 'empirical input' in understandings of health (research) could, by analogy, be referred to as 'aesthetic enrichment'. Underlying to these considerations, we attempt a normative critique of what counts as 'empirical input' and what counts as a 'lived experience'. Delineations of what 'counts' and what doesn't, are a display of 'moral boundaries' – to use Joan Tronto's words – that call for a self-critical examination of positionalities and assumptions. Through these explorative steps this presentation hopes to display a 'boundary testing' of assumptions underlying what counts as 'medicine' or 'health', of delineations between carer-and cared-for, and of delineations between ethics and aesthetics. We believe that, for a medical ethics approach aspiring to include inter- and transdisciplinary perspectives, these are underexplored, yet important questions.

Religion and Bioethics Discourse (AFL-F-121)

Annett Wienmeister

Title: Structuring bioethical debates with the Toulmin model of argumentation – a justificatory dead end?

Abstract: Stephen Toulmin developed his famous model of argumentation in order to facilitate the analysis and development of practical arguments in every day reasoning and science. His approach to arguments is widely recognized in academic disciplines such as law and philosophy and in teaching programs (i.e. in critical thinking courses). In medicine, the "Toulmin model" is used to clarify the use of proof or evidence in clinical reasoning. In the field of biomedical ethics, however, it has received only little attention, just as other methods from the field of argumentation theory. Given the fact that biomedical ethics is a highly discursive and argument driven discipline, the question arises whether the Toulmin model of argumentation can be of any use to clarifying and resolving debates in biomedical ethics. Critics of the Toulmin model argue that, while it helps recognizing arguments that are incomplete, using it in debates of biomedical ethics leads into a dead end. According to them, by using the model one can hardly ever justify a claim, because one of its justificatory elements (the backing) consists of normative ethical theories. These theories, they complain, are themselves highly controversial. The critics leave open whether the inability to justify moral claims in bioethical debates is only a flaw in Toulmins model of argumentation or a characteristic of ethical argumentation per se. The talk begins with a short introduction of the Toulmin model of argumentation. Illustrating a possible debate on "savior siblings", I will then critically assess the rejection of the model by its

critics by drawing on concepts and methods from argumentation theory. On the one hand, I will appreciate the models' merit of detecting incompleteness in arguments, but I will show how the Toulmin model does not carry it through sufficiently. On the other hand, I will reject the critics' objection that the model does not allow for the justification of moral claims. In order to do so, I will introduce a definition of the term "justification" and criteria of good moral reasoning that apply independently of possible controversies in normative ethical theories. I will furthermore argue that identifying those controversies is not a flaw, but instead might elevate the level of justification in debates of biomedical ethics.

Renzo Pegoraro

Title: Biotechnologies, AI and ethics need transdisciplinary dialogue, also involving the public

Abstract: In the innovative bioengineering approaches, molecules and cells are harnessed as "factories," capable of producing "bio-objects" and functions that can significantly impact living systems. They can revolutionize diagnostic tools, therapeutic interventions, and enhancements of biological functions. Notable examples include gene-based therapies for complex genetic disorders, organoid-based engineering using stem cells to grow tissue outside the human body, gastruloids – aggregates of stem cells that have been developed into human models –, and digital twin technology. As these biotechnologies hold profound implications for human health and the human condition itself, ethical considerations must play a central role in their development. AI technologies play an increasingly pivotal role. However, as AI algorithms handle vast biological datasets, they also raise important ethical concerns, such as transparency of AI decision-making, biases in data and algorithms, and the potential for AI to exacerbate inequalities in healthcare access. Furthermore, ensuring that human dignity and autonomy are respected remains a fundamental challenge in clinical applications. Ethical principles (algorethics) such as fairness, accountability, and transparency must guide AI's integration into biotechnology, maximizing benefits without compromising the rights and well-being of individuals. A dialogue between technologists, ethicists, policymakers, and the public will be essential to ensure that biotechnologies (and AI) advancements align with the broader goals of human flourishing and social good. Given the sensitivity of these advancements, addressing these ethical questions requires a transdisciplinary approach in seeking the broadest possible consensus. The involvement of all stakeholders, including the civil society could be relevant and useful. At the epistemological level, significant challenges dot the way: interaction of heterogeneous rationalities, often characterized by profoundly different conceptual approaches, needs to be clarified. Diversities of methodologies and disciplinary paradigms, make dialogue across fields particularly challenging. Furthermore, the use of seemingly well-established concepts can prove problematic: the same term, when applied across different disciplinary contexts, can assume widely varying nuances of meaning. The long-term goal is to outline a shared lexicon capable of fostering more effective interaction among the various disciplines.

Verina Wild

Title: The Place of Marginalization in Bioethics: Do We Need the Concept?

Abstract: Marginalization is widely studied and recognized as a critical topic in health, shaping access to resources, health outcomes, and policy decisions. However, despite its normative significance, its conceptual role in bioethics remains unclear. Thus, this paper critically examines how marginalization – and the inequities associated with it – are engaged within bioethics, analyzing its conceptual usage, its implications for systemic exclusion, and its potential for further normative theorization. By exploring available definitions and how marginalization appears in bioethical literature, recurring patterns and conceptual gaps are identified. The analysis reveals two major findings. First, while definitions from different disciplines provide valuable insights, marginalization has not been normatively theorized as a distinct conceptual category in bioethics. Instead, dynamics of marginalization are largely addressed through existing concepts such as vulnerability or epistemic injustice. Second, it stands out that the contemporary,

redefined understanding of vulnerability in bioethics increasingly incorporates systemic exclusion and structural injustice, raising the question of whether marginalization requires a distinct conceptual lens or if its core dimensions are already encompassed by existing approaches. Consequently, this paper argues that further conceptual debate on marginalization is needed to assess its potential distinct contributions to bioethics. To address this conceptual gap, this paper calls for a more explicit normative engagement with marginalization to clarify its role in bioethical discourse and its implications for equitable health, healthcare practices, and policies.

Giovanni Spitale

Title: On Religious Influence in Bioethics: The Limits of Pluriversalism

Abstract: The World Congress of Bioethics held in Qatar in 2024 (WCB 2024) sparked controversy around the role of religion in bioethics highlighting the need for critical discussions. During the congress there was a strong push for incorporating religious values into bioethical discourse, raising questions about the validity and implications of such an approach. This contribution (based on a paper currently under review in Bioethics) examines the influence of religious thought on bioethical discussions, and the ongoing debate over the role of religious perspectives in this field. Here we explore Jecker and colleagues' pluriversal framework, which was proposed at WCB 2024, espousing a bioethical discourse grounded in civility, respect for law, justice, non-domination, and toleration. While the framework aims to embrace the world's cultural and religious diversity, we suggest that it struggles with significant ethical inconsistencies, poses challenges for pluralistic dialogue, and may be hard to reconcile with human rights. Through an analysis of Jecker's principles and their application, we discuss the difficulty of integrating conflicting religious views with ethical values and with widely accepted human rights frameworks. We then proceed to examine how and why religions might exert undue influence on bioethics; and we argue for a different future for bioethics.

Silke Schicktanz

Title: How should we deal with religiosity as reason for organ donation hesitancy? Empirical results of a survey among European students (N=2163) and ethical reflection

Abstract: Background: Public attitudes are a prerequisite for justifying and implementing legal and ethical efforts to promote organ donation. Knowledge of medical facts and trust are known to be relevant factors for positive attitudes. Religious affiliation has been intensively discussed, with most world religions also advocating organ donation. However, the influence of religion and religiosity, has been analysed only to a limited extent. Aim: We conducted a Europe-wide survey to explore attitudes related to religion and levels of religiosity to gain a better understanding of their impact on public attitudes towards organ donation. Methods: A 36-item survey instrument was developed, asking respondents about their previous experiences, knowledge and personal opinions on transplantation policy, as well as which organs they would be willing to donate and which they would accept. An additional set of socio-demographic questions was included for contextualisation. The survey was conducted between October 2018 and November 2019 among university students from medical and non-medical study programmes in eight European countries: Austria, Belgium, Denmark, Germany, Greece, Romania, Slovenia and Spain. Descriptive and inferential statistical analyses were performed in R. Results: 2193 medical and non-medical students responded. Main results were: 953 stated they were not religious, 358 religious, 640 somewhat religious, 59 very religious and 186 spiritual. Most (1862) said they would donate. Religion and level of religiosity were a relevant factor in acceptance While non-religious, catholic and protestant respondents showed similar patterns of accepting brain death as death, muslim and greek orthodox participants were more likely to reject the understanding of brain death as death. In the case of own organ failure, most students accepted an organ from a brain-dead person. Accepting an organ from a person with no heart activity (NHBD) greek orthodox, catholic, protestant and muslim respondents more often stated that they do not want such an organ or were yet undecided.

Discussion/conclusion: Religion affects whether people are sceptical about organ donation. This raises ethical questions around religious freedom and plurality. When formulating organ donation policies in liberal pluralistic societies, proposals must respect religious freedom and bodily integrity. Health professionals should be trained to be more sensitive to religious attitudes in organ transplantation.

Parallel Sessions III

Genetic Testing, Genome Editing, and Screening (AFL-E-015)

Mariia Maksimova

Title: We Need to Talk About It—Redefining the Right to Withdraw in Therapy Development for ultra-rare diseases.

Abstract: Many patients with ultra-rare diseases suffer from severe symptoms but have no treatment options. Individualized (N-of-1) therapies offer new perspectives by tailoring treatment to a single patient. However, the development processes of these therapies blur the line between clinical research and care, challenging traditional ethical and legal frameworks. One of the challenges here is organizing the patient's right to withdraw, firmly anchored in international law and guidelines. In traditional clinical trials with larger numbers of participants, withdrawal from the study of a single participant does not halt the entire project. In the case of ultra-rare diseases, withdrawal can mean months of work lost, scarce resources wasted, and unique scientific data gone. When a patient withdraws, it's also a loss of potential breakthrough for others. Therefore, a lot is at stake. To balance the participant's right to withdraw with other legitimate interests requires a deviation from the traditional understanding of this right toward a novel interpretation. This study, a part of the TAILORED project, explores how to understand and implement the right to withdraw in a way that respects patient autonomy while supporting research progress. The TAILORED project focuses on developing individualized therapies using a value-sensitive design approach to ensure that moral considerations evolve alongside scientific advancements. Building on biomedical knowledge from the TAILORED research group, previous literature, and reconstruction of the patient journey in individualized therapy development, we identified four key factors important for withdrawal: bodily involvement, uncertainty, mutual dependence between patients and researchers, and resource intensity; all of which evolve through different stages of the therapy development process. Instead of treating withdrawal as a simple yes-or-no decision, this research proposes a staged model that shifts to an ongoing dialogue between patients, researchers, and clinicians, where patients can address their concerns and refine their choices over time. This ensures that withdrawal remains a protected right while also creating opportunities to avoid research waste, gather knowledge on why patients withdraw, and inform future therapy development and ethical frameworks.

Sophie Ayoub

Title: Time poverty of families of children with 22q11DS: A healthcare professional perspective

Abstract: Introduction: 22q11 deletion syndrome (22q11DS) is the most common microdeletion in humans, leading to a wide range of variable clinical manifestations that can affect any part of the body. Most individuals with 22q11DS are diagnosed during childhood and the responsibility of care falls on their primary caregivers, usually their parents, who need to balance the needs of all family members including themselves. This affects parental well-being. This study investigates the perspective of healthcare professionals (HCPs) on the parents' struggle with time invested in caring for their children, factors contributing, the impact of this responsibility and some strategies on how to support the families. Methods: This interview study was part of a larger mixed-methods research initiative aimed at improving the psychosocial well-being of individuals with 22q11DS and their families. The qualitative component

concentrated on gathering insights from HCPs involved in patient care. We conducted qualitative content analysis after transcribing the semi-structured interviews. The research question focused on time poverty within families caring for a child with 22q11DS from the perspective of HCPs. Results: The 20 HCPs interviewed came from diverse professional backgrounds, but all had clinical experience with children with 22q11DS. Our analysis of the data identified three primary themes, centered on time poverty of families caring for a child with 22q11DS. Centralization of care and insufficient coordination were the main modifiable reasons for the time struggle, affecting the families, especially mothers and families living in rural areas. Strategies proposed to mitigate this issue included improved coordination and decentralization of care, and digitalization. Conclusions: Time poverty for families with a child with 22q11DS results from fragmented and uncoordinated medical care, and centralized care disconnected from local care. Better communication between different HCPs, local and central, and a robust support system could enhance these families' well-being and assure an equal distribution of care services without gender bias or exclusion of rural underserved populations.

Marcel Mertz

Title: Ethics under uncertainty, uncertain Ethics? An ethical guidance for the decision to initiate first-in-human trials involving somatic genome editing

Abstract: Technologies targeting gene modification are widely considered as bearing great potential for medical research and practice. One such technology is genome editing (GE), which aims at introducing specific changes in the human genome using several molecular biological methods (e.g. CRISPR-Cas9). Changes induced by GE can either be passed on to the offspring (heritable genome editing, HGE) or not, i.e. somatic genome editing (SGE). First-in-human (FIH) studies involving SGE trigger radical forms of uncertainty, especially with regards to their outcome, their probabilities and their evaluation. Such uncertainty is of a different nature from that intended in the equipoise criteria required to initiate a "classic" clinical trial, as outcomes can often only be tentatively postulated. Also, the use of SGE prompts the consideration of further aspects that contribute to uncertainty: translation of preclinical data in human outcome given species specificities, e.g. different vector sensibility; possibility of side-effects in the (very) long-term; unique and irreversible procedure preventing a classical linear dose-response; impossibility to withdraw from the trial. There is an acknowledged need to complement the current scientific guidelines with ethical guidance specific to this context. For this purpose, we developed a tool structured in (1) a diagnostic step (determining the kind of epistemic uncertainty involved in a specific study), (2) a decisional step (aspects to consider in the assessment of the ethical acceptability of a FIH trial and ethical guidance for the deliberation involving the different assessments), and (3) a communication step (guidance for the communication with potential participants in a study involving considerable uncertainty). The tool thus helps to identify the drivers of uncertainty as well as to reflect on the ethical valuing that may be mobilized to mitigate scarce or incomplete preclinical data. A set of benchmarking questions is suggested to help operationalize the ethical principles that are required for an ethical deliberation, i.e. about the assessment of the value of research and the possible harms linked to it, as well as the proportionality between the two.It is expected that the tool can be applied to comparable technologies such as gene transfer. While a practical test of the tool is still pending, the tool may, on a conceptual level, stimulate further research into the content, relevance and practicality of such tools.

Eva Asscher

Title: Responsible innovation in screening: who determines the necessary information?

Abstract: In the Netherlands the population screening programs for cancer (colon, breast, and cervical) are successful, but participation is declining and the programs do not reach all groups equally. Low SES, low (health) literacy and migration history are correlated with lower screening uptake and worse health

outcomes. In this paper we report on the ethical questions raised by a project aimed at improving the information provision for population screening programs for cancer aimed at groups who are often not reached. In co-creation sessions, the groups were invited to explore the current materials, clarify their informational needs and together improve information materials or develop new approaches.

The information these participants considered important for the decision to participate in screening (or not) was noticeably different from the information which experts consider crucial. For example the information about downsides such as false positives, risks of the screening procedures or worry about the results was frequently considered irrelevant by the participants. Instead the participants preferred practical information about the screening, the advantages and others approaches to improve health and reduce the likelihood of developing cancers. This led to the following question: what information should be included in the cocreated information provision? This became more of a pressing dilemma considering the low (health) literacy which meant that the information should be very clear and information overload should be avoided. This leads to the ethical question what is necessary for valid consent to participate /informed decision making in screening? Here we explore different approaches to informed consent and informed decision making to explore this dilemma. Subsequently we place this dilemma in the context of inherent tension between the (policy) drive for sufficient participation to meet public health goals and true informed decision-making by individuals.

Karla Alex

Title: From Ethics to Practice: Ethical Framework and Best-Practice Recommendations for a Genomic Newborn Screening Program

Abstract: Newborn screening (NBS) is a population-wide screening program, established globally, to detect rare diseases and improve their outcome by early intervention. It is widely regarded as highly successful and is continuously expanded. A genomic NBS (gNBS) is expected as the next innovative and major step in further developing NBS programs. From this, the following question arises, which is addressed in the talk: How should a responsible implementation of gNBS look like, specifically, which ethical criteria should guide the development of gNBS public health programs? We begin by outlining an integrative ethical framework for gNBS programs, based on key principles of public health, research, clinical and childhood ethics and considerations for a learning healthcare system, e.g. the child's best interest, its future autonomy, nonmaleficence, justice and public acceptability. We then translate the ethical considerations from this framework into practice by outlining concrete recommendations for future gNBS programs. With this, we react to the problem that current gNBS pilot studies show notable heterogeneity in selecting target diseases reflecting highly divergent priorities, e.g. opinions differ as to the required degree of certainty of disease outbreak (gene penetrance) so that all newborns should be screened for a disease, or whether genetic information with no health benefit for the child but potentially for relatives (carrier status) should also be included in gNBS. To address this heterogeneity, we developed 11 selection criteria for target diseases, and 7 criteria for management (covering aspects such as consent, access and data storage) of gNBS programs. Developed in a transdisciplinary research group, the criteria are based on relevant expertise from patient representatives, ethics, law, medicine (human genetics and paediatrics) and scholars from medical psychology (who contributed important information from ongoing empirical studies on the German public's views on gNBS). The 18 criteria will be presented by means of examples that best illustrate the underlying ethical considerations. In so doing, we especially focus on key ethical conflicts within a gNBS program, such as between potential harm to the child and a possible research benefit if conditions with lower penetrance are included, and between informed consent requirements and potential harm of refraining from screening, and show how these and further conflicts are addressed in our recommendations.

Manuel Trachsel

Title: Preimplantation Genetic Testing – What are the Ethical Challenges in Clinical Practice?

Abstract: Background: Preimplantation genetic testing (PGT) combines the most advanced reproductive technologies to analyze the genome of an embryo before it is transferred to the uterus. PGT is mainly applied to (a) prevent the transmission of serious familial genetic diseases; (b) to improve pregnancy and birth rates through embryo selection; and (c) to reduce the risk of miscarriage. Regulations on PGT vary globally: some countries prohibit it altogether, while other have specific or no explicit legislation at all. In Switzerland, PGT has been legal since 2017, but it is subject to strict legal requirements to prevent the risk of eugenics and embryo rejection. It must be checked in each individual case whether the following conditions are met: (a) there is no alternative way to avoid the risk of implanting an embryo with a hereditary predisposition for a serious disease, (b) it is probable that the serious disease will manifest before the age of 50, (c) there is no effective or expedient therapy available for combating the serious disease, (d) the couple has informed the physician in writing that they are unwilling to accept the risk, and (e) both parents are able to care for the child until it reaches adulthood. At the University Hospital Basel, the Clinical Ethics Unit facilitates this evaluation process with interdisciplinary clinical ethics consultations (CECs) to determine whether the use of PGT is medically reasonable, technically feasible, and ethically justifiable. Research Questions: What are the demographic and clinical characteristics of the PGT cases discussed in the CECs? What are the most common ethical challenges regarding PGT in clinical practice? What ethical questions arise when applying the Swiss law? In particular, how are the conditions set out in Swiss law applied? Furthermore, what criteria help to decide these questions in an ethically appropriate way in clinical practice? Methods: A quantitative and qualitative content analysis of CEC reports from the University Hospital Basel between 2017 and 2025 was conducted. All reports with a focus on PGT were included in the analysis. Findings: The analysis of more than 50 CEC reports revealed several ethical challenges that arise in clinical practice, particularly regarding the question of whether the genetic condition in question is severe enough to justify PGT, and in cases where the severity of the potential disease's clinical manifestation is uncertain.

Biomedical Ethics session II (AFL-E-011)

Sabine Wöhlke

Title: Objectives and limits of participatory involvement of patient organizations in digital health research

Abstract: BACKGROUND: Patient organisations (POs) can play a key role in collecting and managing health data in databases and in facilitating research. Many health research policies increasingly call for active patient involvement through digitalisation. However, participatory involvement (PI) is ethically and practically different from digital data collection. This raises serious concerns about the ethical underpinnings of 'participation' in digital health, which also need to be addressed in relation to PI. AIM: We conducted a stakeholder conference with 39 representatives of German POs to discuss the opportunities and risks of PI in digital health research. METHODS AND RESULTS: We used a multi-step approach to ensure PI that allows different POs to be involved, which was discussed with our patient advisory board: First, 343 POs were invited to submit remotely short statements on the opportunities and risks of digitalised health research and PI. Second, 45 submitted statements were clustered based on an inductive thematic analysis approach. Points of disagreement and consensus were then discussed at a two-day stakeholder conference. An editorial team consisting of 4 PO representatives drafted a full draft position paper, followed by a remote comment stage for revision. Finally, 39 POs jointly adopted the position paper. The main themes are concerns about unresolved or controversial ethical issues in the use of secondary data, broad consent and low respect for preconditions for the process of co-creation in digital health research. The POs call for a clear definition of the scope and objectives of the PI, as well as professional, financial, human, structural and technical resources as a prerequisite for fairness, transparency and collaboration. CONCLUSION: The multi-stage and interactive process made it possible to develop a common position paper among very different

POs. In order to overcome misunderstandings or misconceptions about PI, ethical guidance on PI procedures is needed, as well as ethical competence on the topic itself.

Tzofit Ofengenden

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

Abstract: 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.

Antonio Maria Giuseppe Staffa

Title: The implementation of the Ethical Space within the ASST of the Seven Lakes: preliminary results of a training course

Abstract: Introduction/Background/Aim: The Espace Éthique de l'Assistance Publique, founded in Paris in 1995, was created to address ethical issues related to health practice and patient care. Since 2023, a project has been approved for the creation of an Ethical Space within the "ASST dei Sette Laghi", such as a place of meeting and discussion dedicated to health workers. With the collaboration of the University of Insubria and the Center for Research in Clinical Ethics (CREC), the first phase of the project was carried out through the design of a training event useful to prepare the moderators of the Ethical Space. The second phase of the project saw the realization of a training event, divided into several meetings, during which through brainstorming and focus were treated themes such as the right to self-determination; the role of guarantor held by health professionals; the protection of patients and their specific characteristics; the principle of freedom; respect for and value of choice; reference to the codes of ethics which guide the activities of health care workers; reflection on personal and professional values. Methods: in the year 2025 a training course was organized characterized by 7 editions, linked to the strategic objective "Humanization of care" of the Management of the Health and Social Professions. The project involved 7 specific areas of the health and care context, which joined for interest and motivation. Results, discussion and conclusions: The proposed project has aroused the interest of 7 specific areas such as: Oncology/Palliative Care Area; Medical and Surgical Area; Maternal-Child/Obstetric-Gynecological Area; Critical Area; Territorial Area; Mental Health Area; Technical-Health Area. The participating professionals expressed their appreciation for the initiative because they were able to share emotional and ethical experiences.

Alessia Bonaccorso

Title: Personalization at the limit of viability: ethical challenges

Abstract: Background: Periviability (22-25 weeks of gestation) presents significant clinical and ethical challenges due to the uncertainty of neonatal survival despite medical advancements. Personalized medicine offers new possibilities for tailoring therapeutic decisions to neonatal characteristics and parental preferences. However, this raises ethical concerns regarding distributive justice, neonatal best interests, and family autonomy. Decision-making in this period is complex, emotionally demanding, and time-sensitive. The interest in "personalization" in periviability highlights the need to adapt interventions and communication to each family's needs. Aims:To examine the ethical implications of personalized medicine in periviability, focusing on its moral justification and the balance between standardized care and adaptation to clinical and value-based needs. Methods:A scoping review was conducted using an interdisciplinary approach integrating bioethics, clinical ethics, and neonatology. International guidelines and relevant literature on key stakeholders' perspectives were analyzed. Results:Personalization can enhance parental autonomy and improve resource allocation. However, tensions arise between equity and individual-based decisions, highlighting the need for flexible protocols that balance clinical criteria with family preferences while avoiding biases and arbitrary choices. Three forms of personalization were identified: Personalized Care: Addresses families' specific needs, fostering trust and parental well-being through psychological support and logistical assistance; Personalized Counseling:Adapts prenatal counseling to parental values, improving trust, comprehension, and decision-making through tailored communication; Personalized Guidelines:Integrates neonatal characteristics to enhance prognostic accuracy and optimize treatments, reducing futile interventions. However, challenges include information overload, parental distress and ethical concerns related to sensitive data collection. Discussion and Conclusions: Personalization in periviability represents a promising advancement but should be guided by justice, proportionality, and shared decision-making. While personalized care and counseling enhance decision-making and family well-being, personalized guidelines pose challenges related to uncertainty and information complexity. Future research should directly involve parents to ensure clinical practices align with their needs and values.

Isaac Moore

Title: Dialogues beyond dispensing: pharmacy professionals' understanding of conscientious objection in Great Britain

Abstract: Pharmacy professionals (pharmacists and pharmacy technicians) are healthcare professionals identified as experts in medicines who provide pharmaceutical care. Conscientious objection (CO) in pharmacy is an issue of both public and professional concern. Topical issues include conscience-based objection to involvement in the provision of abortion, assisted dying, gender affirming care, and personalised medicines. A traditional approach to conscientious objection has been ethical theorising without input from stakeholders, thus neglecting the diverse views of those in practice. A minority of scholars argue that healthcare professionals should never be permitted to opt out of providing lawful services. Most commentators, however, take a position that it is appropriate to accommodate CO to some extent. There are several approaches to limiting the scope of CO, but prior to this project these normative questions have been answered in debate amongst ethicists. Historically, physicians and nurses have been well represented in these debates. To date, however, pharmacy professionals have had minimal involvement and attention in the discourse on CO. Two recent studies have begun to address this in the context of abortion (Maxwell et al., 2021) and professional guidance (Fovargue and Neal, 2022). My ongoing PhD research, funded by the Economic and Social Research Council (2023-2026), includes pharmacy professionals in these debates by engaging them in open dialogue to share understanding and situate normative discernment in practice. In this talk I draw on empirical and theoretical insights from my ongoing research to explore diverse understandings of conscientious objection amongst pharmacy professionals. These have been derived from preliminary analysis of semi-structured (online/in person) interviews with

pharmacy professionals (n=25). I will explore how these findings are situated, reflecting on my own (pre-)understandings and experience as a pharmacist and bioethicist. Secondly, I will demonstrate how these fit into the methodological schema of the wider PhD project, which builds on the existing body of scholarship in utilising a dialogical empirical bioethics methodology applied to the pharmacy context. In conclusion, co-creation and collaborative reflection involving pharmacy professional voices are essential in the face of changing practice and innovation, and extremely timely, given ongoing momentum to legalise assisted dying in the British Isles.

Ethics of Emerging Care Technologies (AFL-E-022)

Eva Meier

Title: The impact of telemonitoring on the responsibilities of patients and caregivers

Abstract: Using telemonitoring to remotely monitor patients' health, diagnose medical conditions, and to adjust prescription regimens, demands a shift of traditional roles and responsibilities of patients and caregivers. Unclear responsibilities for validating patient data and follow-up actions, can have serious consequences. For instance, the FDA recently revoked a home telemonitoring device after critical notifications on deviating cardiac rhythms had failed to reach cardiologists, resulting in two patient fatalities and hundreds experiencing health issues. Recent ethics studies highlight responsibility concerns in telemonitoring that facilitates care-at-a-distance, yet empirical ethics research on its impact on caregiver and patient roles remains limited, emphasizing the need for real-world research. To investigate this impact, we studied a Dutch cardiology telemonitoring program called HartWacht. For this study we interviewed 30 patients and caregivers in HartWacht by means of Q-methodology. We identified 4 distinct narratives on how patients and caregivers interpret their roles and responsibilities when using telemonitoring: “Balancing act: subtle responsibility shift and conflicting responsibilities among caregivers”, “Isolated responsibility: patients and caregivers as separate actors”, “Responsibilized but not alone: the independent patient in a web of shared accountability” and “From hands-on to hand-in-hand: the major responsibility shift of nurses and shared care delivery”. The narratives agree on three key points: first, patients are responsible for taking accurate measurements, as this is essential for successful telemonitoring; second, all narratives acknowledge that telemonitoring shift nurses' responsibilities, though the extent varies; and third, technology developers are generally held accountable for device reliability, while caregivers are responsible for using the data in decision-making but not for its accuracy. Besides these agreements, these narratives differ on multiple points: the extent to which patients’ responsibilities shift in managing their own data, how nurses' roles shift in medical decision-making, and whether care-delivery responsibilities should be shared or individually defined. These findings provide insights for developing implementation guidelines, training programs for patients and caregivers, and mentoring initiatives to help navigating new roles and responsibilities in telemonitoring-based care.

Lena Stange

Title: How to combine care technology and care responsibility? Ethical considerations

Abstract: Responsibility for care arises when people are dependent on care activities that have to be provided by others. The responsible parties are those who are generally able to act and can be held responsible or accountable for their actions. The use of technologies to support and relieve those involved in healthcare can lead to changes and shifts in responsibility for care. Responsibility for care is attributed differently to the actors involved and also to the technology. There has been a lack of systematic research into the complex interplay of responsibilities, technological approaches and different stakeholder groups, especially with regard to cross-sectoral care pathways. It is possible, for example, that the responsibility for care diffuses when human actors rely on technologies. In the context of new (care) technologies, the

attribution of responsibility for care in different stakeholders such as carers, relatives, care managers or researchers requires analytical clarification and ethical evaluation. Against this backdrop, we explored the question of what implications the inclusion of care technologies has on (attributions of) responsibility in the context of care. In the talk we present a theoretical framework that can be applied to ethically analyse different distributions of care responsibilities, which takes into account the stakeholder groups, contexts of action and technologies involved in different care pathways and in their dynamic interaction. This conceptualisation can serve as a basis for an ethical analysis of the responsible use of technology in care. For this purpose, network-related concepts of responsibility are used and refined in order to consider the different interests, roles and normative logics of action individually, put them in relation or combine them with each other. Within the framework of individual, professional, organisational and technical ethical perspectives, the attribution and distribution of responsibility for care in the context of the use of care technologies between the actors and settings will be examined. By considering constellations of responsibility, it is possible to gain a more comprehensive understanding of responsibility for care including technology, so that the roles and responsibilities of the various groups of stakeholders can be appropriately analysed and evaluated.

Andreea-Iulia Somesan

Title: Patients' Engagement in Meaningful and Responsible Development of Wireless Targeted Drug Delivery: A Survey on Romanian Population's Familiarity, Attitudes and Ethical Concerns

Abstract: The interdisciplinary and complex nature of implementing targeted drug delivery therapies using wireless-guided nanocarriers raises significant ethical dilemmas, public controversies, and potential resistance. As a result, emerging biotechnologies, particularly in the field of nanomedicine, are often met with scepticism due to uncertainties regarding their impact and long-term implications. This pilot study, conducted at the Cardiology I Clinic in Cluj-Napoca between April and June 2024, explores the ethical considerations and public perceptions associated with these therapies, shedding light on key factors influencing their acceptability. While the study primarily assessed participants' familiarity, attitudes, and ethical concerns, for some respondents, this was their first exposure to nanotechnology and its potential clinical applications in targeted drug delivery. The discussion section of this paper highlights how survey-based studies can serve as valuable models for promoting meaningful public engagement in the development of next-generation biomedical technologies. This approach yields significant benefits for all stakeholders: research institutions and investors gain insight into public attitudes toward their innovations, while patients not only receive foundational information on the subject but also have the opportunity to reflect on ethical challenges and their future medical decisions regarding novel therapeutic interventions.

Anna-Eva Nebowsky

Title: The Impact of Medical Technologies on Partner Relationships: Ethical Considerations

Abstract: Medical technologies are often designed with a primary focus on the individual patient. However, in areas such as caregiving, decision-making, and chronic disease management, these technologies also significantly impact the patient's partner and the dynamics of their relationship. Ethical discussions have so far paid little attention to how medical technologies reshape autonomy, responsibility, and role distribution within partnerships. Partners frequently assume essential caregiving responsibilities that affect their well-being and dynamic in their relationship. In home care, smart technologies–such as GPS trackers or intelligent emergency systems–can provide relief by increasing safety but may also introduce concerns about surveillance, privacy, and autonomy. Similarly, care robots or AI-driven assistance systems can support physical caregiving tasks, yet some partners may experience a loss of closeness or a shift in their caregiving identity. While technology can make caregiving more efficient, it also reshapes the dynamics within the relationship. This presentation aims to discuss the impact of technological use on both the

patient and the involved partner, taking into account the effects on their relationship. Drawing on the four principles of medical ethics, it will be demonstrated why an individualistic perspective is insufficient and how the couple's relationship can be more effectively integrated into ethical considerations. The principle of autonomy traditionally prioritizes the patient's wishes. However, in caregiving relationships, both the patient's and the partner's autonomy must be considered. Technological interventions that benefit the patient may diminish the partner's autonomy or create power imbalances. Additionally, while technologies improve patient outcomes, they could emotionally harm the partner, violating the principle of non-maleficence. The principle of justice adds complexity, as caregiving responsibilities are often unevenly distributed, particularly in households where gendered expectations shape caregiving roles. Technologies that alleviate caregiving burdens may also perpetuate or exacerbate these disparities. This talk argues for an ethical approach to medical technologies that considers both the patient and the partner. By integrating relational dynamics into ethical considerations, we can ensure responsible implementation strategies that respect both individuals in caregiving relationships.

Debora Spagnolo

Title: Gendered Perspectives on Deep Brain Stimulation in Parkinson's Disease: Evolving Needs, Expectations, and Perceived Outcomes

Abstract: Introduction: Deep Brain Stimulation (DBS) for Parkinson's disease (PD) is effective in mitigating motor symptoms, but its psychological and psychosocial impacts remain underexplored, particularly from a gender perspective. Patients have distinct support needs and seek different types of information when deciding to undergo DBS. Then, postoperatively, they navigate complex adjustments to the device and new disease stages. Yet, whether and how these experiences differ between genders remains unclear. Beyond biological differences in symptom manifestation, non-biological factors - such as disparities in health-related quality of life, access to advanced therapies, and variations in care environments - significantly shape healthcare decisions. Understanding these nuanced factors is essential for addressing existing gaps in care and promoting equitable treatment. Objectives: This study explores the perspectives, needs, and experiences of men and women with PD before and after DBS, identifying both similarities and differences in their decision-making processes and postoperative adaptation. Methods: We conducted semi-structured interviews at two time points: 4.1 months preoperatively and 9.9 months postoperatively (n=10; 7 males, 3 females). Thematic analysis was used to identify patterns in patients' evolving expectations, challenges, and perceptions through a gender lens. Additionally, semantic network maps were employed to visualize longitudinal thematic patterns within the narratives of men and women. Results: Preoperatively, most patients reported feeling adequately informed, though men and women approached decision-making differently. Men were more likely to actively seek detailed information, whereas women tended to rely on their medical team's guidance or trusted their partners for technical details. Postoperative interviews revealed shifting perceptions of DBS benefits, with new needs and expectations emerging as patients adjusted to the device's long-term effects. Gender differences in adaptation and support-seeking behaviors were identified. Conclusions: Our findings provide practical insights to enhance patient- and gender-centered care, support realistic expectation management, and improve shared decision-making for men and women with PD. In conclusion, this study advocates for a holistic care model that addresses the distinct needs of individual patients, acknowledging also the role of gender in shaping them.

Alice Cavolo

Title: Ethical Reflections on Organizing the First Human Trial of Artificial Womb Technologies

Abstract: In 2017 Partridge et al. announced the first successful animal trial with an artificial placenta, a technology meant to improve the survival and quality of life of preterm infants. The first in-human trial is expected in the next 2-5 years. This trial will pose notable challenges. For example, how do we predict risk of

a trial with an innovative and potentially disruptive technology and how do protect participants? Further, as transfer in AP requires a C-section, the pregnant person is also a participant. How do we balance the interests of both participants? And how do we balance the interests of science with the interest of participants? To answer these questions, we compared randomized controlled trials and single arm trials to understand which trial design best balances the interests of science and participants. We also compared AP trials with comparable settings to understand how to protect participants. We believe that randomized trials might hinder both the interests of participants and science. Randomized trials might fail in reaching a sizeable sample, which could pointlessly expose participants to risks. Furthermore, parents who choose to participate in the trial might expect to receive AP. Failed expectations might distress parents and hinder the therapeutic relationship. A single arm trial could prevent some of the methodological and ethical challenges of the randomized trials. To understand how to protect participants we considered the two steps of trial separately. First, transfer into AP involves two participants: the mother and the fetus. As AP requires a C-section, the procedure cannot be carried out without the mother's consent regardless of fetal benefit. Second, treatment in AP involves one participant: the infant and the parents have equal rights. The partner cannot oblige the mother to participate, but what if the partner request withdrawal? We believe that interrupting the trial in this case would invalidate the risks sustained by the mother during the transfer so unless both parents agree on withdrawal, the trial should proceed. However, if the infant is not reacting well, then AP should be withdrawn. Better decisional tools should be developed to avoid this issue, e.g. showing an AP.

Public Health Ethics (AFL-F-121)

Gemma García Calderó

Title: Protecting Affiliation During Pandemic Crises: A Capabilities Approach for Public Health Ethical Deliberation

Abstract: During the time of Covid-19 pandemic when vaccines were not yet developed, non-pharmaceutical interventions (NPIs) reducing social contacts were widely implemented. The extent to which restrictions were imposed on social contacts was unprecedented, embracing society as a whole and lasting for several months in some countries. NPIs had an impact on the population's social resources, putting many people at risk of failing to meet their core social needs. These refer to our needs for (1) social connections that ensure our personal security and meaningful prospects for well-being, and for (2) contributing to others' survival and well-being according to our abilities. WHO's report on social protection measures shows that no measure to protect social relationships was put in place during Covid-19 pandemic. This evidence calls for an articulation of the grounds for striking the balance between pandemic contention goals and protection of core social needs in public health ethical deliberation. However, so far, ethical considerations regarding the contention of infectious diseases have typically focussed on the confrontation between individual rights of privacy and autonomy and the public benefit of reducing transmission to others. Subsequently, this piece of work aims to argue for the ethical relevance of core social needs in public health deliberation in pandemic response measures. In the first part, we fundament the normative importance of core social needs by drawing mainly on the 'Philosophy of Need' developed by Soran Reader, as well as on Martha Nussbaum's 'Capabilities approach'. In the second part we analyse which grounds justify an influence of core social needs on NPIs in the specific context of a pandemic, by exploring their relationship with public health ethical principles. This paper provides an original normative account which relies on three main aspects. First, it focusses on the concept of core social needs as defined by Kimberly Brownlee, which captures from an objective standpoint the moral demandingness of supportive human connection. Second, it recognises the irreplaceable role of personal relationships, by contrast to other accounts which overlook the need for a minimum protection of those and favour exclusively non-human or online interactions. Third, it upholds that core social needs should be integrated in deliberation processes and not just in mitigation strategies, and thus, become a formative element of NPI planning.

Mirko Ancillotti

Title: Ethical Justifications for Ensuring Global Access to Antibiotics: Insights from Stakeholder Perspective

Abstract: Antimicrobial resistance (AMR) poses one of the most pressing public health challenges. The continued efficacy of antibiotics is essential not only for treating infections but also for enabling routine medical procedures such as surgeries, chemotherapy, and organ transplants. However, the overuse and misuse of antibiotics have led to rising resistance, threatening to render these life-saving drugs ineffective. Ensuring sustainable antibiotic access requires balancing individual rights with societal responsibilities, raising key ethical questions in global health governance. Who should bear the costs and burdens of antibiotic stewardship? How should policymakers navigate tensions between immediate clinical needs and long-term public health goals? This study applies the 3D Value Framework Model to examine how various actors—including healthcare professionals, policymakers, and pharmaceutical industry representatives—justify strategies for maintaining antibiotic availability. The model conceptualises antibiotics' value across three dimensions: patient consumption value, relating to individual health benefits; population-level value, considering broader societal and public health implications; and preparedness value, accounting for antibiotics' role in safeguarding future health security. This study explores how stakeholders engage with these dimensions to inform ethical antimicrobial stewardship. As the first phase of a larger research initiative, this qualitative interview study will explore how these actors frame ethical and practical justifications for securing antibiotic access and what trade-offs they consider necessary in balancing individual needs with collective responsibility. Semi-structured interviews will be conducted, and thematic analysis employed to identify common themes and divergences in stakeholder reasoning, shedding light on ethical considerations shaping decision-making in public health policy. Findings will guide a quantitative study on public perceptions of antibiotic access and sustainability. This mixed-methods study will clarify how societal actors perceive ethical and policy challenges in AMR. By bridging empirical research with ethical theory, this study seeks to contribute to discussions on responsible antibiotic use, justice in healthcare access, and governance in tackling AMR at local and global levels.

Michiel De Proost

Title: DIY Medicine, Empowerment, and Resistance: Exploring Outsider Innovation in Healthcare

Abstract: Several scholars argue that today's information technologies are enabling so-called do-it-yourself (DIY) medicine. For instance, the Open Artificial Pancreas System (OpenAPS) movement has been fostered by thousands of people with type 1 diabetes worldwide, making innovation more accessible to laypersons. A dominant trope in the literature is to perceive such forms of DIY medicine as an empowering, participatory model of engagement, in contrast to traditional approaches to the practice of medicine. However, other scholars highlight a close connection between DIY medicine and traditional institutions of medical science or the market. This presentation aims to map out the ambiguous role of empowerment in DIY medicine. Before assessing the thorny questions surrounding the relationship between DIY medicine and empowerment, we provide some background on DIY medicine. Next, we explain how the new power granted to individuals through DIY medicine and technological tinkering dialectically fosters feelings of vulnerability and precarity. Lastly, we reflect on the resistance potential of DIY medicine.

Biomedical Ethics session III (AFL-F-121)

Alessandra Agnese Grossi

Title: “One, No One and One Hundred Thousand" Types of Moral Distress: Findings from a Qualitative Study of Moral Distress Experience Among Italian Healthcare Professionals

Abstract: Introduction: Moral distress (MD) among healthcare professionals (HCPs) has gained considerable attention, largely due to challenges experienced during COVID-19. Yet, despite extensive research, debates persist regarding its definition, causes, and implications. Some scholars, including Morley et al. (2020), propose expanding MD to include distress from moral constraint, conflict, uncertainty, dilemma, and tension. This study examines whether Morley’s MD categories effectively describe MD experiences among Italian HCPs. Methods: A convenience sample of 20 HCPs (11 physicians, 7 nurses, 1 obstetrician, 1 physiotherapist) from a hospital in Northern Italy participated in semi-structured interviews describing morally distressing situations. Results: We identified 66 morally distressing situations, 42 aligning with Morley’s framework: 26 stemmed from constraints, 14 from conflict, 1 from uncertainty, and none from dilemmas. Six cases involved multiple causes, while 17 stemmed from a new cause, namely misconduct. Throughout the coding process, we also found that all identified causes led to MD because they implied a perceived “Violation of professional values and norms”. This violation emerged as a necessary condition for MD, leading us to develop a multi-layered model positioning “Violation of professional values and norms” as the deep cause of MD, with constraint, conflict, uncertainty, and misconduct as surface causes. Discussion: Morley’s framework does not fully capture MD’s complexity. Additional sources of MD, such as misconduct, suggest that other triggers may be identified depending on the contexts. Moreover, our findings indicate that all MD triggers stem from a perceived threat to professional values and norms. Defining MD solely by its surface causes risks fragmenting the concept and overlooking its core mechanism: the perceived compromise of professional integrity that leads to distress. Conclusions: Institutional policies should protect professional values to prevent and manage MD. Ethics consultations and psychological support may enhance communication, support ethical decision-making, and address the emotional consequences for HCPs affected by MD. Expanding ethics training, fostering open dialogue, and establishing clear guidelines may further help HCPs align their actions with their professional values.

Mária Rajka

Title: Lack of innovation and inequities in the Romanian health system. The patient’s viewpoint

Abstract: Introduction: Equal access to health resources and the question of inequities in health is one of the core concerns of today’s bioethics. Based on this principle of equity in health, we have conducted an expert-oriented qualitative research in 2024 in Cluj county in Romania, and now we would like to present also the viewpoint of the patient when talking about the national health system. Methods. This study will collate a general opinion about innovation and inequities in the Romanian health system by using the method of an online survey. Discussions. Poor administrative organization, geographical inequalities, the lack of professionals in some specialities are some of the causes of inequities, but at the fundament there is also the lack of national policies for innovation of the health system. Conclusions. Innovation in health and the problem of inequity in the context of the Romanian health system must be studied for the reason we can work on awareness, encourage communication of the involved parties, and search for solutions.

Francesca Reato

Title: The construction of the Clinical Ethics Consultant Competencies' Repertoire in the light of the European and Italian Qualifications Framework: results of the interviews to the double

Abstract: Background/aims: For public recognition of the Clinical Ethics Consultant (CEC) qualification, it is necessary a Competencies' Repertoire that meets the criteria of the European and Italian Qualfications Framework (2017, 2018). Methods/Materials: To achieve data saturation, a qualitative ethnographic study was conducted according to the principles of "At Home Ethnography." Twenty "interviews to the double", lasting 90 minutes each, were conducted with professionals who manage clinical ethics consultations. The interviewer assumed the role of the "double." Results and discussion: 11 women and 9 men offered their input, enabling the identification of competencies and expected outcomes (expressed in terms of knowledge, skills, autonomy and responsibility), also interesting differences between the realities in which they practice. Some argue that the Bioethicist has the necessary competencies to conduct consultation, others argue that it is not enough to be a Bioethicist. Some practice in the Clinical Ethics Services, in cooperation with multiprofessional team or individually, involving sometimes the Ethics Committees for the multiprofessional component necessary and the medical legal implications that consultation may have, other practice in the Ethics Committees. Some are contacted in view of their previous experience in CEs or because they have attended post basic training. Some call themselves Clinical Ethics Consultants or Bioethicists or Researchers, others carry out the consultations through the role of forensic physician, moral philosopher, public health physician, etc. Some CECs relate with assisted person and family members/caregivers, others only with clinicians or all professionals involved, not just health care. Phone calls, e-mails and dedicated portals are the most frequently used methods for inquiries. Some CECs prefer improvisation during consultation, others use specific Case Analysis Models. Some CECs find psychological support useful for more complex cases that have led to disquiet, others prefer to find solace in Expert Colleagues. Conclusions: The Interviews with the double, in addition to the identification of the competencies, allowed for indirect entry into the context of reference, through the participants' narratives and unspoken invitation to enter their "professional life place" and "live it." The exchange of roles allowed to understand in-depth understanding of the work and reasons for CECs' practices, fostering reflexivity.

Poster Session II (Olivenhalle)

Kevin Dzi

Title: Physicians' encounters with discrimination in the course of their work as healthcare providers: a qualitative systematic review

Abstract: Background: Globally, there has been an increase in reports of discrimination and violence against physicians. Physicians may encounter discrimination from patients, families, or colleagues while practicing medicine. Discrimination against physicians results in stress, exhaustion, and elevated work turnover rates. The current shortage of physicians in the healthcare sector is exacerbated by these findings. The doctor-patient interaction must consistently embody mutual respect. Regrettably, this is typically not the situation. The majority of the literature highlights the significance of physicians treating their patients impartially and fairly while abiding by the four principles of medical ethics: autonomy, beneficence, nonmaleficence, and impartiality. It is, however, essential to address issues such as discrimination and other adverse behaviours faced by physicians, given the increasing prevalence of these problems. Multiple studies have documented physicians' discrimination. It's important to compile as much evidence as possible so health institutions and other stakeholders may combat physician discrimination and violence and improve their quality of life. Systematic reviews are helpful for combining evidence from multiple articles. Methods: A qualitative systematic review was conducted to aggregate all existing evidence on the topic of discrimination against physicians in clinical settings, utilizing the PRISMA reporting guidelines, the JBI critical appraisal checklist for qualitative research, and the JBI extraction tool for qualitative research. Results and conclusion: Following the extraction and synthesis of data from 125 studies, the subsequent themes emerged: gender discrimination (subthemes: career advancement, sexual harassment, questioning of roles), discrimination

based on race, nationality, religion, and ethnicity, lack of recognition as credible health professionals, and patient refusal of treatment. Only a small number of studies discussed victim support strategies. Discrimination was reported to impact physicians' health, performance, and motivation. While many people are speaking out against prejudice against patients, we also need to address the prejudice that doctors face. When physicians and medical personnel are accorded respect and offered optimal working conditions, they are better equipped to serve their patients.

Ceren Polat

Title: Exploring the Ethical and Technical Considerations of GRACE, A Voice Assistant for Dementia Care

Abstract: Digital assistive technologies are promising tools to enhance the quality of life for people with dementia (PWD) by facilitating cognitive engagement, independence, social interaction, and reducing caregiver burden. Among these, voice-based assistive technologies are advantageous due to their affordability, accessibility, and personalized interactions. They do not require high digital literacy and offer a natural style of communication, enabling easier interactions for cognitively impaired individuals. When enhanced by large language models (LLMs), such voice assistants can better simulate human-like interactions, assist with personalized daily tasks, and provide individualized lifestyle interventions to support PWD in maintaining their independence. Despite their benefits, it is paramount to ensure responsible integration of voice assistants into dementia care by addressing ethical challenges such as preservation of autonomy and dignity. Additionally, incorporating AI-driven technologies introduces concerns of privacy, bias, and misinformation. As PWD may not fully understand data collection and use, it is the responsibility of researchers to ensure a consent process which supports informed decision-making. Moreover, trust and deception are rising concerns, as PWD can form anthropomorphic emotional attachments with voice assistants, raising questions about the extent to which LLMs should simulate human-like responses. Given that people can have varying symptoms and severities of dementia, this creates a challenge for voice assistants to be personalized and adaptable to the different stages and symptoms of dementia. Dementia-related speech impairments can make it difficult for LLMs to correctly interpret user input, leading to frustration and decreased engagement. Moreover, proactive AI behavior, where the voice assistant initiates interactions, must balance helpfulness and intrusiveness to avoid overwhelming users. This paper presents GRACE, an LLM-based voice assistant designed to provide lifestyle and cognitive interventions for PWD. Using principles of Value-Sensitive Design combined with an Ethics by Design approach, we aim to identify the core moral values necessary for trustworthy and ethical AI development. These frameworks help integrate ethical principles into design requirements for LLM-based voice assistants, fostering responsible healthcare innovation that improves user experience, well-being, and support while respecting individual values.

Tobias Eichinger

Title: A digital toolbox to support competency-oriented ethics teaching in health-related subjects and professions: Results of the KOMETH-Learn project

Abstract: With the shift towards competency-orientation, ethics teaching in health-related subjects and professions is faced with the task of not only imparting knowledge to students, but also enabling them to develop relevant ethical competencies. Ethical competencies include the ability to align professional activities with ethical standards and to reflect on these critically. This presents teachers with the challenge of developing suitable learning objectives, didactic methods and assessment tools. The working group “ethik learning” of the Academy of Ethics in Medicine (AEM) is dedicated to support teachers in this challenge by promoting and further developing competency-oriented approaches in ethics teaching. To this end, the working group initiated the project “KOMETH-Learn (Developing, applying, reflecting on and using competency-oriented ethics teaching)”, which is funded by the Stiftung Innovation in der Hochschullehre.

With this poster, we would like to present the results of KOMETH-Learn, focusing on a digital toolbox developed as part of the project. The digital toolbox provides teachers with a collection of cases and tried-and-tested teaching concepts. Cases refer to descriptions of situations in which moral uncertainty, a moral conflict, a moral dilemma or morally questionable actions are made visible and which can therefore open up discussion in teaching and space for reflection. We understand teaching concepts as descriptions that not merely represent a teaching method (e.g. marble group), but refer to a specific learning objective relevant to the teaching of ethics and explain how the learning objective is to be achieved and, if necessary, assessed. Teaching concepts can address smaller teaching units (e.g. 2 hours cours) or whole modules spanning a semester. Within the toolbox, content can be filtered according to criteria such as subject area and thus adapted to the individual requirements of the teaching context. The toolbox is designed as a growing collection allowing the donation of cases and teaching concepts. A standardized process for donation has been developed. Submissions are reviewed by an editorial team to ensure the high quality of the teaching and learning materials provided. A prototype of the toolbox has already been published on the website of the working group in German (https://www.medizinethiklehre.de/toolbox/) and can be tried out with a tablet as part of the poster presentation.

Jonas Karneboge

Title: Beyond Disclosure: Supported Decision-Making for Alzheimer's Patients in the Biomarker Era

Abstract: With advances in biomarker-based detection of Alzheimer's disease (AD) and new disease-modifying treatments (DMTs), we face fundamental ethical challenges balancing patient autonomy, beneficence, and non-maleficence in early-stage AD care. This shift in diagnostic and therapeutic capabilities creates tension between early intervention benefits and potential harms from disclosure, particularly when considering patients with cognitive impairment. Currently, there is a knowledge gap regarding ethical counseling and disclosure practices in early symptomatic disease stages, and how to balance truth-telling with potential psychological impact of dementia risk estimation. We examine the ethical dimensions of capacity to consent in patients with mild cognitive impairment eligible for DMTs, analyzing how cognitive limitations challenge traditional informed consent models. Our analysis (1) addresses the ethical implications of capacity assessment in vulnerable populations and (2) proposes a supported decision-making framework that respects autonomy while providing necessary protection. We argue that standardized assessment tools must be complemented by patient-centered communication strategies to enhance understanding of complex risk-benefit profiles. This approach balances respect for patient dignity and self-determination with the ethical obligation to protect those with diminished capacity, offering a model for ethical care in the evolving therapeutic landscape of neurodegenerative diseases.

Lara Bernasconi

Title: Towards a Clinical Large Language Model – An Ethico-Legal Case Study Analysis

Abstract: Large Language Models (LLMs) are advanced artificial intelligence (AI) technologies capable of performing natural language processing tasks and having various potential applications in healthcare. However, there are few clinical LLMs, and no models have been trained using extensive Swiss electronic health record data. While this approach holds promise, the development of such a model raises significant regulatory and ethical challenges. This paper explores these challenges through a case study of a Swiss initiative leveraging high-performance computing to train a clinical LLM using unstructured medical data. We address key issues, beginning with the applicable regulations and the complexities of bridging technical and human research. We then analyse challenges related to data security and compliance with data minimization requirements, followed by an examination of the complexities of communicating with study participants to ensure informed consent and meaningful public engagement. Our discussion is framed by data protection principles and offers recommendations for researchers, ethics committees, and policymakers within the Swiss research landscape. We argue that the responsible development of clinical

LLMs requires a coordinated effort among all stakeholders, emphasizing the need for harmonized practices and a clear regulatory framework. Open and transparent dialogue between researchers, ethics committees, regulators, and patients is essential. Additionally, lagging regulations and practices, such as those related to anonymization and general consent, must be updated to address emerging challenges. Ultimately, a holistic approach is needed to balance ethico-legal considerations with the effective development of clinical LLMs. This work contributes to the ongoing discourse on trustworthy AI in healthcare, providing insights to guide the evolution of ethical and regulatory frameworks governing the development of clinical LLMs.

Andrea Glässel

Title: Game-based learning as an approach in interprofessional training of health professionals based on ethical case scenarios

Abstract: Ethical decisions in healthcare are inherently complex. They often involve conflicting values, professional roles, and interests, and must be made under time pressure with incomplete information. Teaching ethical decision-making, therefore, requires more than theoretical instruction: it must allow learners to experience and reflect on real-world dilemmas. Game-based learning provides an innovative approach by immersing students in realistic, emotionally engaging situations and encouraging perspective-taking. At the centre of this interprofessional course at ZHAW Zurich University of Applied Sciences is the digital learning game UMED. Originally developed at the Institute of Biomedical Ethics and Medical History (IBME), University of Zurich, for medical students. UMED has been adapted for five bachelor's programmes in the health professions: Physiotherapy, Occupational Therapy, Nursing, Midwifery, and Health Promotion & Prevention. UMED presents narrative, interactive case scenarios drawn from clinical practice. Topics include informed consent, discrimination, overtreatment, judgment and decision-making capacity, conflicts of interest, role tensions, and problematic value systems. Students work in tandems and interprofessional small groups to explore these cases, apply communication models, reflect on empathy and professional conduct, and practice conveying complex information appropriately. Structured learning diaries and peer discussions deepen reflection and promote self-awareness. Through the game's three core scenarios, students gain insights into medical reasoning and transfer these to their roles. The change of perspective fosters a better understanding of interdisciplinary collaboration and supports ethical competence in their specific fields. Students report high engagement and a strong added value in exploring medical viewpoints. The interactive format encourages them to assess their ethical assumptions more critically and strengthens their decision-making in morally challenging situations. Based on the positive learning experience with UMED, students in health professions would also like to see learning scenarios on ethical dilemmas from their inter- and professional fields of action. The course ultimately supports health professional students in recognising and addressing morally questionable behaviours, developing professional judgment, and engaging meaningfully in interprofessional ethical dialogue.

Nabila Puspakesuma

Title: ETH-MUD (Ethics Muda/Young Ethics): Investigating the ethics of responsibility-shifting for mental health through digital mental health in young people in Indonesia

Abstract: While digital mental health (DMH) technologies are argued to promote empowerment and autonomy, concerns over these technologies potentially shifting the responsibility for mental health towards the users have also emerged. For young people, especially those from low and middle income countries where access to services is often significantly limited and stigma against mental illness is prevalent, these concerns might be highly relevant. This study aims to critically investigate whether responsibility for mental health should be shifted onto young people through the use of DMH in low and middle-income countries, with Indonesia as an example. A scoping review was first conducted to map out existing theories and arguments, evidence, and understandings of personal responsibility in the context of

digital health. The study employed participatory approach through the involvement of an Indonesian Young People Advisory Group (YPAG), together with qualitative methods in the form of focus group discussions (FGDs) for data collection. A total of 33 young people aged 17-24 who had experience accessing DMH from two regions in Indonesia were involved in the FGDs to explore their understanding and exercise of responsibility for mental health in the context of the use of DMH. This presentation will discuss some initial findings from the data against frameworks including but not limited to different types of responsibility and responsibilisation, as well as other relevant principles such as agency and justice.

Alina Roua Solomon

Title: The contribution of clinical ethics consultation to decision making in complex psychiatric conditions: an explorative qualitative study

Abstract: Context: Ethical dilemmas are common in clinical psychiatry, often requiring healthcare professionals to balance the four principles of biomedical ethics. With the evolution of medicine and shared decision making, psychiatrists face complex situations demanding them to respect the patient's wishes while providing beneficial therapeutic solutions. Several publications highlight the useful role of clinical ethics consultation (CEC) in analyzing complex cases and the importance of offering training for mental health professionals. Yet, the exact contribution of clinical ethics consultation to resolving ethical issues in psychiatry remains understudied. Objectives: The first objective of the study is to (1) identify the most common requests for CEC by clinical psychiatry (2) to describe how the principles of biomedical ethics are mobilized during the analysis of the case, as per the report. The second objective of this study is to determine if and what guidelines could be proposed for a more preventive and systematic approach to ethical problems in this specific context. Method: This is a retrospective, qualitative document analysis of CEC reports concerning psychiatric patients at a university hospital over a period of 5 years (2018-2022). Data consists of 30 reports, identified and pseudonymized by the CEC, and 4 interviews with the ethics consultants. The method of analysis is thematic analysis, using a combination of deductive and inductive approaches, with 50% of data being cross-coded. Results: The mean age for patients is 44 years. The main (66%) reason for requesting CEC reviews is coercion under its 3 forms: pharmacological treatment, institutionalization, and investigations. Preliminary findings suggest that autonomy, beneficence, and institutional contingencies are common decision-making challenges that psychiatrists need to navigate. Discussion: By mapping ethical dilemmas and evaluating the role of ethics consultations, this study aims to contribute to a more structured approach to ethical decision-making in psychiatry. Findings may assist clinical ethics committees and psychiatric institutions in developing proactive guidelines to address recurrent ethical challenges, enhancing quality of care, and reducing value-related conflicts.

Salvatore Simone Masilla

Title: Qualitative study to evaluate the Clinical Ethics Consultation service (VALUE)

Abstract: The Clinical Ethics Consultation (CEC) Service provides decision-making support in complex clinical cases, helping healthcare professionals, patients and families in the ethical decision-making process. This service has been available at the Fondazione Policlinico Universitario 'A. Gemelli' IRCCS (FPUG) since 1992. To date, it is difficult to evaluate the service due to the complexity of the factors involved. The aim of this study is to explore two key questions: Who is the clinical ethics consultant—or who should they be—for HCPs? And what impact does the CEC have on the act of care? This qualitative study examines various aspects of the CEC to identify the essential criteria for evaluating its effectiveness, efficiency, and user satisfaction. This prospective qualitative study employs semi-structured face-to-face interviews with HCPs who have previously utilized CEC at FPUG. Each interview includes 16 questions, starting with personal experiences in a CEC, then covering care, communication, collaboration, and moral reflection, before concluding with a methodological analysis. Using the "funnel technique," the dialogue moves from broad

topics to the research focus. Domains and quality indicators were derived from literature analysis. To avoid bias, PhD students, not the consultant, conducted the interviews. A hermeneutic analysis of the topics is then performed to understand the impact of the CEC in clinical practice. Some HCPs view the service as a tool for facilitating communication with patients or supporting interdisciplinary decision-making. Others see the consultant as valuable for personal ethical reflection and professional training. Other themes concern the training of the consultant, the quality of the service (positive aspects emerge such as the ability to resolve complex situations, and negative aspects such as a longer reporting time compared to other consultancy services). A common proposal from HCPs involves the development of a satisfaction questionnaire to be administered to various stakeholders following each consultation. The study highlights not only the expectations of those who request CEC, but also the adherence of the service to them. The interviews reveal the satisfaction of the CEC applicants, particularly in their responses regarding the quality of the expertise provided for moral reflection and the role of the consultant in promoting interdisciplinary cooperation.

Beatrix Göcking

Title: Integrating Sex and Gender in Swiss Intensive Care Research

Abstract: Women are underrepresented in ICUs and receive fewer invasive treatments than men. Additionally, in biomedical research, there is a persistent lack of representation for women and sexual and gender-diverse individuals. To explain this bias appropriately, research must encompass sex and gender-related aspects in current research. Due to bureaucratic, institutional, and practical constraints, the systematic collection of sex- and gender-related data to investigate the ICU gender gap is hindered. We examine recommendations on sex and gender equity and the methodological limitations of integrating these dimensions into ICU research. Swiss law explicitly addresses the consideration of those socio-demographic factors in the design and implementation of studies, ensuring equitable representation. The European Association of Science Editors Sex and Gender Equity in Research (SAGER) guidelines were edited more inclusively in 2024 by the Swissethics National Board. They recommend describing the study population with consideration of sexual and gender diversity and capturing sex-related dimensions (hormonal levels, gene expression), gender-related dimensions (identities, norms), and sexual orientation dimensions (sexual and romantic attraction). Health institutions collect socio-demographic data aligned with the civil registry based on binary categories that are not aligned with SAGER recommendations. Data collection during ICU stays is limited due to inappropriate circumstances for gathering detailed sex and gender-related histories. Patients often cannot provide information themselves, and their next of kin are frequently overwhelmed, facing existential decisions. Researchers, ethics committees, and reviewers must recognize the serious implications of incomplete data. The lack of sex and gender data collection reinforces biological reductionism, neglecting behavioral dimensions and excluding sexual and gender-diverse individuals. To drive institutional change and ensure comprehensive, sex- and gender-sensitive care in the ICU, we call for immediate action in two key areas: (a) strengthening sex- and gender-sensitive education for health professionals, and (b) aligning demographic data collection in health institutions with SAGER recommendations. A first step would be to adapt the admission form and the next of kin questionnaire to systematically capture sex and gender-related dimensions, paving the way for more inclusive and evidence-based critical care.

Parallel Sessions IV

Biomedical Ethics session IV (AFL-E-015)

Jasmin Barman-Aksözen

Title: Unjustified placebo-controlled trials? The case of the ultra-rare disease erythropoietic protoporphyria

Abstract: Background: Erythropoietic protoporphyria (EPP) is genetic disease (prevalence: 1:100.000) characterized by an intolerance to visible light. In 2014, the European Medicines Agency (EMA) recommended approval of afamelanotide, the first treatment that effectively increases the time patients can spend in sunlight and improves their quality of life. During the evaluation, the EMA had assessed that additional placebo-controlled trials would not be ethically acceptable, because patients in the control arm are at risk of developing severe and untreatable pain. However, a new drug for treating EPP, dersimelagon, is currently investigated in clinical trials with a placebo-control arm. The Declaration of Helsinki requires that any new intervention must be tested against the best proven intervention, except for compelling and scientifically sound methodological reasons. We wanted to know whether there are any identifiable methodological reasons that justify the use of a placebo control group when assessing dersimelagon for treating EPP. Method: We analyzed the publicly available clinical trial protocols of afamelanotide and dersimelagon with the aim to identify methodological reasons that might justify the use of a placebo control group. Result: We did not find, in our assessment, any compelling reasons that would justify a placebo-controlled clinical trial for the assessment of dersimelagon for treating EPP. On the contrary, by their mode of action, both afamelanotide and dersimelagon lead to an increase in skin pigmentation ("tanning") in a considerable part of the trial participants: In placebo-controlled clinical trials, neither the participants nor the investigators are supposed to have knowledge about the treatment allocation as this might introduce various biases. By assessing dersimelagon in trials that use afamelanotide as an active control, blinding of the trials would be established as a tanning effect could be caused by either one of the substances. Head-to-head studies in which two treatments are investigated against each other have been successfully conducted in other ultra-rare diseases. Conclusion: Head-to-head studies directedly assessing dersimelagon against afamelanotide would be the ethically and methodologically sounder trial design. In our talk, we would therefore like to discuss the question of why ethical review boards, principal investigators and regulatory agencies accepted the current trial design for dersimelagon.

Julian W. März

Title: Age-Based Exclusions in Gene Therapy Trials: Current Practices and Ethical Considerations

Abstract: Gene therapies are revolutionizing modern medicine, offering the chance of a cure to children and caregivers affected by hitherto incurable rare diseases. As of early 2025, twelve gene therapies for non-oncological indications have received FDA approval, with hundreds more currently in clinical research. However, these therapies also carry serious risks, including potentially lethal immunogenicity, oncogenicity, and unknown long-term effects. Despite the potential for paediatric benefit, children are frequently underrepresented or entirely excluded from gene therapy trials. This exclusion limits both their access to innovative therapies and the relevance of trial outcomes for the paediatric population. Children's participation, however, introduces complex ethical challenges. Traditionally seen as a uniformly vulnerable group, children have often been excluded in the name of protection. Yet, emerging ethical frameworks advocate for a more differentiated and inclusive approach. The evolving concept of vulnerability – reflected in recent updates to the Declaration of Helsinki (2024) and CIOMS guidelines – emphasizes not just individual incapacity but also contextual and structural inequities. These documents highlight that excluding vulnerable populations can perpetuate health disparities and call for their responsible inclusion, accompanied by appropriate safeguards. Regulatory bodies, including the FDA and EMA, increasingly

encourage paediatric participation and advocate for child-focused trial design and review. This presentation will explore current practices and ethical considerations regarding the inclusion and exclusion of children in paediatric gene therapy trials. It will present empirical data from clinical trial registries, identify patterns of age-based exclusion, and examine ethical and regulatory trends promoting broader inclusion of children in gene therapy clinical trials.

Ana Gurau

Title: The Roles of Advocacy Organisations in Clinical Research

Abstract: Advocacy organisations (AOs) are increasingly involved in clinical research on various diseases, specifically as representatives of persons affected by the disease. As novel actors with unique and variegated features, their roles in clinical research are complex and understudied. Ethical justification, guidelines, and evidence on the impact of this trend have not yet been researched thoroughly. By using the case of neurodegenerative diseases, specifically the dementia syndrome, this article investigates the ethics of AOs' involvement in clinical research. To explore this question, I develop an analysis framework that applies Emanuel et al.'s general requirements of ethical clinical research to dementia. The article draws from two main data sources. First, desk research of publicly available documentation allows understanding the breadth of the phenomenon. Second, semi-structured interviews with representatives of AOs allows going deeper into specific cases and the interactive dynamics of AOs' involvement in clinical research. I find that AOs can assume a wide array of roles in clinical research. A five-part typology is proposed that systematises them: advocate, research community builder, investigator, member of a research consortium acting as a sponsor, and funder. I stress that these results are not mutually exclusive, and AOs may choose to fulfil multiple such roles in parallel. As each role raises specific challenges and potential contributions to the ethical conduct of research, it becomes particularly important to discern how AOs act as representatives of affected persons, mainly people with dementia and informal caregivers. A framework for scrutinising the legitimacy of AOs in this sense is proposed. The study generates qualitative evidence on the implications for research ethics of AOs' involvement in clinical research on dementia. As partners with potential to represent affected persons in clinical research, dementia AOs have a duty to ensure and continuously reinforce their legitimacy. As a determinant of AOs' legitimacy in speaking 'on behalf of' the affected communities, the concept of throughput legitimacy is mobilised to ensure that persons with dementia and caregivers are meaningfully involved in clinical research.

Tilsim Kadioglu

Title: Ethical Challenges in Personalized Medicine: Equity, Privacy, and Genetic Discrimination

Abstract: Personalized medicine, which customizes medical treatment to an individual's genetic, environmental, and lifestyle factors, presents significant ethical challenges. One of the most pressing concerns revolves around equity and accessibility. When access to the advanced technologies used in personalized medicine is unevenly distributed, there is a risk that these innovations will primarily benefit privileged groups, typically the wealthy or those living in developed countries. As a result, personalized medicine may widen the healthcare gap between affluent and low-income patients. Ensuring fair access to genetic testing and targeted therapies is becoming increasingly difficult, raising concerns that personalized medicine could exacerbate existing health disparities, particularly for disadvantaged populations. Another critical issue is privacy and data protection. Genetic and personalized medical data are highly sensitive, raising concerns about ownership and potential misuse. If insurers, employers, or governments gain access to genetic information, individuals may face discrimination or breaches of confidentiality. Striking a balance between patient privacy and the need for medical research and innovation remains a complex challenge. To address these concerns, effective regulatory frameworks must be put in place to protect genetic information while still enabling scientific progress. The complexity of personalized medicine also highlights concerns about informed consent. Many patients may not fully understand the risks, limitations, and long-term

implications of genetic testing or personalized treatments. As medical data and treatment options become increasingly sophisticated, ensuring that patients can make truly informed decisions becomes more challenging. Healthcare providers have a responsibility to ensure that patients receive clear, comprehensible information before consenting to personalized medical interventions. One of the most urgent ethical concerns in personalized medicine is genetic discrimination. If insurers or employers have access to an individual's genetic data, they may use it to deny coverage, adjust premiums, or make hiring decisions based on perceived health risks. Without strong legal protection, many individuals may avoid genetic testing altogether due to fears of discrimination. Addressing this issue requires robust anti-discrimination laws and policies that prevent genetic information from being misused.

Rodrigo Lopez-Barreda

Title: Ethical Dimensions of Short-Term Medical Missions: A Justice Framework Analysis

Abstract: Short-Term Medical Missions (STMMs) are projects in which healthcare professionals volunteer their expertise to provide medical services in low- and middle-income countries (LMICs). These missions often target underserved, rural, or poor populations and may offer general medical care, surgery, dentistry, or specialized services such as ophthalmology. STMMs raise significant ethical questions about their effectiveness, impact, and ethical challenges. The concept of justice provides a valuable framework, with interpretations varying across different philosophical accounts. This article aims to analyze STMMs through the lens of three major ethical frameworks: Utilitarianism, Contractualism, and Cosmopolitanism. The research is conducted in two stages. First a literature review on the main concepts to examine how each ethical framework addresses the moral dimensions of STMMs. The second stage applies these frameworks to practical scenarios drawn from the authors' experience with STMMs. Preliminary Results: Initial findings from the literature review provide distinct insights into the ethical dimensions of STMMs: Utilitarianism faces the challenge of measuring and aggregating the utility of different individuals. In the context of STMMs, a utilitarian analysis would first consider the utility generated for the local population. The global interconnectedness demonstrated during the pandemic suggests that STMMs could have broader benefits, which would maximize utility. However, the cost-effectiveness of such missions raises concerns, as well as the potential conflicts of interest. John Rawl's theory of justice could be an example of contractualism because it is based on social agreements within political communities. In this context, the obligation to ensure fairness in the distribution of opportunities falls within the boundaries of the political community. Thus, while STMMs can make significant contributions to alleviating health inequities, they are not morally required by justice. Iris M. Young offers a cosmopolitarian account of global justice, which emphases that moral obligations arise from the nature and intensity of interactions between individuals and communities. In a globalized world, these interactions often occur through complex and indirect channels in which individuals do not directly engage with those experiencing injustice, but their participation in broader economic, social, and political systems contributes to sustain structural inequalities.

Trust, Disinformation, and Global Bioethics in the Age of AI (AFL-E-011)

Kiarash Aramesh

Title: Health Disinformation, Artificial Intelligence, and the Role of Global Bioethics

Abstract: Health disinformation in the forms of health-related pseudoscience and antiscience has become a significant global challenge, especially during and after the COVID-19 pandemic. The emergence and popularity of social media platforms has created a new virtual environment where disinformation can proliferate rapidly and efficiently by utilizing marketing and attention-seeking tactics. Artificial intelligence (AI) is increasingly being relied upon by healthcare professionals, patients, journalists, students, and other groups around the globe to seek health-related information. Language models exhibit considerable difficulty distinguishing scientific facts from disinformation when generating outputs. Therefore, their popularity only exacerbates the problem of health disinformation at local and global levels. The purveyors

of health disinformation, including the practitioners of medical pseudoscience, can also exploit AI to create their content or make it more appealing. Therefore, the governance of AI needs to be guided by a comprehensive ethical framework. The bioethics community, currently formulating ethical guidelines for applying AI in healthcare, must recognize the critical vulnerability of AI output to be infiltrated or exploited by health disinformation and medical pseudoscience. Therefore, a robust attention to the necessity of implementing provisions for fact-checking in AI tools and applications should be part of such guidelines. Such ethical frameworks and guidelines are necessary not only at the national level but also at the level of global governance to minimize the harmful consequences of health disinformation in the era of AI.

Sarah Savić Kallesøe

Title: What Does It Mean to Trust? Investigating the Conceptualizations of Public Trust in Healthcare Systems from an Empirical Bioethics Perspective

Abstract: Public trust is essential for effective healthcare systems, shaping how individuals engage with care and comply with public health initiatives. However, public trust in healthcare is often conceptualized differently than how it is measured empirically, leading to a misalignment that can undermine the trust metric validity and the efficacy of healthcare policy. My research investigates these conceptual and empirical gaps to improve how trust is understood and measured in healthcare.

Jelena Vanhollebeke

Title: Citizens' perspectives on the ethics of health technology innovations

Abstract: Background: Health Technology Innovations (HTIs) entail material novelties aimed to solve health problems and improve quality of life. These innovations have changed and will continue to change the way healthcare is delivered – from self-monitoring at home to machine learning and highly specialized robotics in clinical practice. Recognizing HTIs as a phenomenon fully embedded in society, its ethical discussion should move beyond the healthcare settings and involve the broader community. We therefore aim to collect qualitative data on the perspectives of citizens on the ethics of HTIs, as to complement the existing theoretical research while promoting citizen science and participation. Methods: A focus group study is currently being conducted with groups of five to eight Belgian citizens, living in Flanders and aged at least 18 years old. Participants are initially recruited through social media and subsequently by collaborating with carefully selected socio-cultural organizations. The theoretical sampling approach is hereby applied, as early study results are used to increasingly focus participant recruitment. Moreover, data analysis is performed simultaneously with data collection and used to further refine the process of data collection, in accordance with the Grounded Theory Design. Data analysis itself is then based on the Qualitative Analysis Guide of Leuven (QUAGOL), in which a holistic understanding of the data precedes and defines the coding process. Results: Preliminary results suggest that Flemish citizens perceive HTIs as a means to improve quality of life. It is however feared that the existence of HTIs might shift the focus of healthcare to mere longevity and invoke medical futility. Other dualities seem to appear in the participants' ethical discourse, as HTIs have the potential to both improve and challenge values such as autonomy, equity, trust, accessibility, and digital and health literacy. Lastly, HTIs are often contrasted with human aspects of care. HTIs are thereby expected to serve as a complement and not a replacement to care given by humans. Conclusion: This focus group study provides a first glance into the perspectives of Flemish citizens on the ethics of Health Technology Innovations. Their reflections are hoped to enrich the existing ethical discourse by acknowledging and including the inherent socio-historical context in which HTIs are designed, developed and used.

Wenke Liedtke

Title: Ethical Responsibility in Digitalized Healthcare: Structural Challenges and Constraints

Abstract: The rapid advancement of scientific and digital innovations transforms healthcare. Healthcare professionals are expected to work with technologies using artificial intelligence (AI) in various disciplines, but this raises pressing ethical questions about assuming responsibility and leads to moral dilemmas. AI-driven systems like clinical decision support systems often operate in ways that are opaque, limiting professionals' ability to oversee or justify their outcomes. Yet, a relational understanding of ethical responsibility presupposes an understanding of the processes leading to a potential outcome as well as the possible consequences of actions and alternatives. To assume responsibility, healthcare professionals must have been able to acquire such knowledge. This creates an ethical dilemma in work reality, as healthcare professionals are constrained within their control and oversight of such systems. Especially institutional constraints—such as time pressures, resource scarcity, and regulatory frameworks—limit ethical responsibility in digitalized healthcare, leaving healthcare professionals with little room for ethical deliberation in their work environments. This talk highlights the gap between ethical reflection and work reality, questioning under what conditions healthcare professionals can assume ethical responsibility. In doing so, this provides an impulse for reflection on ethical responsibility in the context of the digital transformation of healthcare. Starting with a theoretical understanding of responsibility as a relational concept, the fundamental requirements for assuming responsibility in the context of AI-driven systems are outlined. This is followed by an analysis of how these requirements intersect with systemic constraints in healthcare, such as time pressures, resource limitations, education and training, and regulatory frameworks, shaping professional responsibility. Next, the examination looks at how these constraints impact ethical decision-making, particularly in relation to Beauchamp and Childress' biomedical principles. Systemic conditions create a gap between ethical expectations and the practical realities such as the tension between using and understanding digital technologies, balancing time with economic pressures, and the lack of training. Finally, the talk explores how these structural constraints influence the ethical landscape of healthcare and their implications for responsible innovation.

Anja Pichl

Title: Integrating ethics with science and technology development. A reflection on goals, methods, potential pitfalls and future perspectives

Abstract: A closer integration of ethics with science and technology development (STD) has been called for in recent bioethical debates. Various models of ethics integration have been proposed such as ‘embedded ethics’, ‘collaborative ethics’, ‘real-time ethics engagement’ and ‘engineering ethics’. They seek to closely engage with and have an impact on or even ‘guide’ STD as it unfolds. This talk analyzes aims, methods, potential issues and future perspective of integrating ethics with organoid research, neurotechnology and medical AI. Results: Close collaboration with scientists is indispensable for important purposes of bioethics such as research oversight and ethics education for scientists and engineers, which can lead to greater ethical awareness and better scientific practice. However, the integration of ethics with STD in its currently dominant forms tends to limit the scope and depth of ethical analysis and to exacerbate long-criticized problems of bioethics concerning its understanding of and relationship toward science, its theoretical basis and its socio-political role. I’ll argue that (i) for an ethics of STD there is an urgent need to make more use of other sources of knowledge on science and technology as part of social transformation processes, e.g. science and technology studies, social theory, history and philosophy of science etc. On such a broader epistemic basis, ethical issues of STD and potential solutions can be identified which go beyond the rather narrow scope of understanding and action of scientific and engineering practice. (ii) This broader perspective can also contribute to achieving the more specific goals of identifying research ethics issues and striving for ethical impact on STD from its conceptualization onwards as the examples of modeling human diversity in organoid research (Hinterberger 2025) and the LEED framework “for recentering questions of ethics and justice in the research process” (Reardon et al. 2023, 894) illustrate. The further development of

ethics integration should rest on a broader epistemic basis, clarify its normative foundations and goals, resist the pressure to be useful for STD and exercise political self-reflectiveness and humility by contributing to, rather than replacing, processes of public deliberation and democratic decision-making.

Gert Helgesson

Title: On the value conflict between scientific knowledge production and fair distribution of authorship

Abstract: A common assumption in medicine and medical research ethics is that scientific knowledge is valuable and that there is an imperative to do research. Another widely shared assumption is that only those who have contributed sufficiently to the work should be credited with authorship. The correct handling of academic authorship is widely recognized to be of ethical importance, particularly for its relevance to fairness in the distribution of academic credit among researchers, but also to ensure transparency, correct handling of the scientific record, and the proper allocation of accountability for the work. However, what is rarely discussed in the literature is what to do in situations where there is a conflict between these values, i.e., when fairness in authorship attribution stands in the way of gaining new scientific knowledge. This presentation focusses on this value conflict. While such conflict may be easily avoidable in theory, either by encouraging resisting research partners to fulfill authorship requirements or by avoiding collaboration when this is not feasible, it is an issue in real life when persuasion is not possible, or is perceived as too risky, and abandoning concerned research interests seems unreasonable. Different solutions to this value conflict will be explored, using common collaboration contexts, such as that between pre-clinicians and clinicians or that between holders of highly useful research resources and those willing to use them in new research, as “test cases” for the proposed solutions.

Mental Health, Education, and the Ethics of Care Infrastructures (AFL-E-022)

Annika Rohrmoser

Title: Addressing loneliness across diverse populations: an umbrella review

Abstract: Loneliness, defined as the distressing gap between desired and existing social connections, is a pressing public health concern. Evidence linking loneliness to adverse health outcomes is growing. While psychological interventions have shown promise, their effectiveness remains uncertain. Diverse populations, who have been historically excluded from social and health resources, are disproportionately affected by loneliness but have not been centered in research aiming to address loneliness. This umbrella review aims to (1) identify suitable interventions in addressing loneliness across diverse populations, (2) classify them into emerging categories, and (3) identify the key features that contribute to their success. This umbrella review was prospectively registered with PROSPERO (CRD: 42024600184) and is being conducted in accordance with the Joanna Brigg’s Institute’s recommendations for umbrella reviews. Five databases were systematically searched for systematic reviews synthesizing evidence on loneliness interventions for historically marginalized groups. Title, abstract and full-text screening was conducted by two independent reviewers, along with quality assessment. The results will be synthesized narratively, highlighting key themes, patterns and variations in effectiveness across interventions. Preliminary analyses suggest that across diverse population groups, interventions addressing loneliness at the individual level are frequently insufficient. This umbrella review will address the critical gap in understanding how loneliness affects people that have been historically excluded from social and health resources by synthesizing evidence on the effectiveness of intervention addressing loneliness across diverse populations. The knowledge gained will aid the development of precise, effective interventions to address loneliness, with significant implications for public health policy and practice.

Anna Westermair

Title: An International e-Delphi Study on Futility in Mental Healthcare

Abstract: Background: The concept of futility emerged in intensive care but has recently gained attention within the mental healthcare (MHC) literature, e.g. in the debates surrounding palliative psychiatry and medical assistance in dying for a mental disorder as the sole underlying condition. However, these debates are hampered by the concept of futility being ill-defined, especially in the MHC context. To address this research gap, we explored whether and how possible futility should be assessed and addressed in MHC with the aim of achieving consensus recommendations. Methods: We recruited 93 international professional experts and experts by experience to participate in a modified e-Delphi study. Based on a systematic literature review on futility in MHC, a first qualitative Delphi round captured experts' understandings of futility. Discussing these findings with select experts led to a procedural framework for assessing and addressing futility in MHC. The ensuing quantitative Delphi rounds served to clarify ambiguities and assess the level of agreement with each framework element among the expert group. All statements of the final framework met the predetermined consensus criterion of 75% in round 3. Results: Experts had heterogenous conceptualizations of futility but agreed that futility is an important intuition signalling the possibility that the treatment in question should not be pursued. We identified four distinct ethical reasons for this conclusion. For example, treatment should not be pursued when it is baseless (defined as there being no rational reason to assume that the treatment in question can have the intended effect(s)). While two of these reasons (e.g., treatment being baseless) fall into the zone of professional discretion, the other two (e.g., treatment being harmful) should be assessed and addressed in a shared decision-making process. Importantly, determinations that a treatment should not be pursued are not final but need to be re-evaluated when the underlying facts or values change. Discussion: Just like intensive care, MHC is confronted with limitations. Our procedural framework for assessing and addressing possible futility in MHC may promote clarity in ethical debates about dealing with these limitations. In addition, it may help MHC teams and their patients use intuitions about futility productively, namely as a trigger for re-evaluating the current or planned care plan and possibly adjusting course.

Wanda Spahl

Title: Relational Autonomy in Digital Mental Health Games: Rethinking the Balance Between Autonomy and Social Play

Abstract: Digital serious games are increasingly used to support those struggling with mental health challenges such as depression, anxiety, and stress. While these new technologies promise positive health outcomes, they also raise critical ethical questions with regard to autonomy. These include concerns about users' decision-making autonomy in managing their mental health, potential dependence on digital tools for emotional regulation, the balance between personalization and algorithmic control, and the extent of users' agency over their data and privacy. Less attention, however, has been given to the concept of autonomy in digital mental health games designed to foster social connections between users. Such games aim to promote collaboration, social skills, and reduce loneliness. For example, recent research highlights how Human-Computer Interaction studies on technologies aimed at relating people have largely overlooked autonomy, focusing excessively on the collective "we" while neglecting the needs of individual "I"'s (Wenhart & Hassenzahl, 2024). My concrete example is the augmented reality mental health game LINA , developed within the Horizon Europe project ASPbelong. Designed for adolescents, it facilitates in-class collaborative play to strengthen their sense of belonging. Players work in pairs and larger groups to solve puzzles, often with limited in-game choices to effectively enable teamwork. This approach restricts autonomous play as traditionally understood in gaming, where players are typically free to make independent choices and explore the game environment. As member of the interdisciplinary development team behind LINA, I reflect on designing and testing collaborative game elements for and with young people. I propose a relational autonomy perspective, drawing from feminist bioethics, to reframe restrictions on autonomous play as beneficial for fostering social connections. This talk explores ethical

considerations as a key aspect of interdisciplinary mental health research and innovation. Using concrete game examples, it examines the complementary and conflicting roles of autonomy and social connectedness in digital mental health serious games.

Christiane Vogel

Title: Evaluation of a course on interprofessional ethical case consultations and reflection on the contribution and challenges of training in ethical competencies

Abstract: Introduction: The training of ethical skills is increasingly the subject of student courses. The professional knowledge and value-relevant perspectives of different health care professions can make an important contribution to case-related ethical analyses, such as those occasionally carried out in the context of ethics case consultations. The aim of this contribution is to present and evaluate an interprofessional course for acquiring the knowledge and skills needed to carry out such counseling, as well as to discuss the contribution and challenges of interprofessional teaching for ethical competence development. Methods: The course consists of six teaching units: two units providing a theoretical introduction to the methodology of principle-oriented ethics case consultation, followed by four units simulating two (anonymized) ethics consultation cases. The students take on both the role of the participants and that of the moderator. The moderation and counseling are reflected on by the course instructor and the students in a feedback session. The target group is medical students, students of evidence-based nursing, and midwifery. The written evaluation takes place imme-diately after the event. Results: The course has been held three times since winter semester 2022/2023, and 96 evaluation forms could be evaluated (response rate: 78%). On a five-point Likert scale (1= “strongly agree”), students reported, among other things, a “positive change in attitude towards interprofessional collaboration through the course” with a mean of 1.8±0.8 and “sensitization to various ethical dimensions in terms of professional activity” with 1.6±0.9. The free texts show that the students particularly benefited from the practical exercise, the real cases and the exchange among each other. Discussion: According to the evaluation, the simulation of ethical case consultations offers a good starting point for interprofessional courses on ethical competencies. Due to the required multi-professional perspective in such a setting, students learn to deal with the competing perspectives, values and moral concepts of others. The discussion will focus on the specific contribution of interprofessional courses to the training of ethical competencies and the challenges associated with this approach.

Adam Parkes

Title: On-Demand Medical Ethics Education: Exploring the value of digital resources to support healthcare ethics and law education for medical students

Abstract: Medical students now routinely supplement their education with the use of on-demand digital resources, with smartphones having been described as a “learn anywhere” resource. Research has found daily usage of medical education mobile apps and websites to be common, as well as myriad motivations for use. Ranging from resource banks to interactive practice assessments, these online offerings are now a fixture of the medical education landscape – including after graduation. However, coverage of ethics and law within these resources is limited at best. This project explores the motivations of UK medical students in using educational digital resources, with a particular focus on ethics and law. Through a two-stage national survey of students across all UK medical schools, we are examining (a) the usage patterns and preferred functionality of existing digital resources, and (b) the would-be interest in and expectations of a dedicated medical ethics and law digital resource. At a later stage of the project, findings from this survey will form the basis of a collaborative workshop involving ethics and law academics working in UK medical education. We will present the preliminary analysis of our national medical student survey on the use of medical education digital resources, with a particular focus on the anticipated value of a dedicated medical ethics and law

resource. Exploring medical students' expectations of ethics and law education will be invaluable to any later resource development, as well as providing broader insights into how medical students perceive their ethics and law education. Whilst our focus in this project is on UK medical students, we anticipate our findings having utility in other countries and healthcare professions given the extent of the on-demand education boom across the health sector.

Melanie Werren & **Kristin Hammer**

Title: "Ethics for all": interprofessional ethical training in the education of healthcare professionals

Abstract: The presentation introduces the teaching and learning concept "Ethics for All," designed to promote ethical reflection, discussion, decision-making, and collaboration within interprofessional teams in the healthcare sector. The training enables participants from various healthcare professions to collectively resolve challenging dilemma situations from practice. It fosters the development of professional competences (reflection and problem-solving), social competences (communication and collaboration), and personal competences (self-reflection, tolerance for ambiguity) (Genner, 2019). Through this approach, students acquire 21st-century skills (Genner, 2019). The learning unit uniquely integrates the three dimensions of interprofessional collaboration, ethics, and communication. The teaching and learning concept, along with the associated teaching materials, was developed by an interprofessional team of lecturers at the Zurich University of Applied Sciences (ZHAW). This concept has already been successfully implemented, evaluated, and refined multiple times in the education of healthcare professionals, including occupational therapists, health promoters, midwives, nurses, physiotherapists, physicians, and social workers. Through insights gained from the implementation and evaluation process, a comprehensive teaching and learning concept has emerged that addresses the three dimensions mentioned earlier. The concept incorporates ethical case examples based on real-world practice scenarios and e-learning units that are interprofessionally transferable. The foundation for reflection is provided by the decision-making framework for ethical reflection by Wallimann-Helmer & Keller (2017). Co-creative teaching methods foster group processes and shifts in perspective. The audience is introduced to a best-practice concept designed to promote joint learning and collaboration in the context of ethics. The practice cases that form the core of this concept address multiple professions. According to Riedel (2024), the ethical competence cultivated through this approach enables well-founded ethical decision-making, enhances the quality of care and therapy, and can positively impact the experience of moral distress.

End of Life (AFL-F-121)

Settimio Monteverde & **Oliver Matthes**

Title: From "clean rules" to "dirty hands"? Development of an ethical guideline on assisted suicide in a Swiss hospital

Abstract: Switzerland is known for its "civil model" of assisted suicide. Based on the Criminal Code, competent persons can request suicide assistance, which is usually provided by right-to-die organisations. According to the Swiss Academy of Medical Sciences, physicians willing to comply with the patient's wish may respond to such requests as a personal, conscientious act, if certain medical and procedural criteria are met. However, according to a recommendation of the National Ethics Advisory Board, acute care institutions may refuse or limit access of right-to-die organisations to hospitals on the assumption that patients are only hospitalised for a limited period of time and are not 'residents'. As a result, patients who are eligible for assisted suicide may not be able to carry out their wishes in the hospital environment. They may therefore either die in a different way than they would prefer, or they may have to leave the hospital under undignified conditions. This places complex ethical demands not only for the hospital team, but also for relatives, general practitioners, or residential care facilities who look after the patients only for a limited period of

time. Drawing on our experience as clinical ethicists in a large Swiss-German university hospital, we describe the ethics committee's delicate path both in responding to the moral burden reported by patients, families and professionals when faced with such requests in hospital, and in evaluating national and international experience to inform possible policy change. Importantly, although the hospitals' old policy formally provided for exceptions, it did not describe them at all, leading to great uncertainty in dealing with patients' requests. In the process of policy adaptation, we present the perspectives of different stakeholders, describe the role of the clinical ethics committee in guiding the various steps of discussion and negotiation towards a policy change that 1) concretizes the situations in which assisted suicide can be provided in the hospital, 2) addresses the complex needs of a highly vulnerable population for whom respect for self-determination is paramount, but also 3) the need for safety and freedom of conscience for healthcare professionals. Finally, based on the international literature and our experience in Switzerland, we discuss possible risks and opportunities for the role of clinical ethics structures in the process of introducing and monitoring hospital assisted dying practices.

Costanza Raimondi

Title: Ethical challenges in End-of-Life decisions: an umbrella systematic review of attitudes among physicians, nurses, and the general public in Europe

Abstract: Introduction: End-of-life (EoL) decisions are ethically complex, requiring a balance between patient autonomy, professional responsibility, and societal values. Euthanasia, physician-assisted suicide (PAS), withdrawal or withholding of life-sustaining treatment, palliative sedation, and advance care planning (ACP) evoke divergent attitudes among healthcare professionals (HCPs) and the general public. Understanding attitudes is crucial for ensuring ethically sound healthcare policies and patient-centered care. This is what ELISI project (Attitudes towards End-of-Life Issues in Italy), funded by the European Union and the Italian Ministry for Universities and Research, aims to address. Aim: To examine the attitudes of European physicians, nurses, and the public toward EoL decisions, in order to identify key trends, ethical concerns, and policy gaps in EoL care. The ELISI project seeks to fill the gap by contributing to the promotion of ethically responsible innovation in EoL practices. Methods: An umbrella systematic review was conducted. A systematic search in Medline, CIANHL, and PsycINFO (01/2010-06/2024) identified systematic reviews on EoL attitudes in Europe. A narrative synthesis was applied to integrate the findings. Results: Out of 587 identified studies, 11 met the inclusion criteria, and revealed significant variations in attitudes. The public exhibited strongest support for euthanasia and PAS, viewing them as expressions of autonomy. However, individuals were more conservative when deciding for relatives, highlighting emotional complexities and moral considerations involved in EoL choices. Nurses showed cautious but open attitudes toward assisted dying practices. Their involvement in direct patient care shaped ethically sensitive perspectives, but role ambiguity and institutional constrains limited their role. Physicians held the most conservative attitudes, citing ethical and legal concerns and the risk of coercion or misinterpretation of patient wishes. Discomfort with ACP discussions stemmed from timing challenges, disease unpredictability, and uncertainty about practices. Attitudes toward palliative sedation and treatment withdrawal varied greatly. Poor interdisciplinary communication often delayed treatment withdrawal decisions. Conclusions: Findings emphasize the need for standardized frameworks, clearer ethical guidelines, better interdisciplinary communication, and public and professional education to bridge gaps in EoL choices.

Carlos Gomez-Virseda

Title: Conscientious Objection in Euthanasia and Assisted Suicide: A Systematic Review

Abstract: Introduction: As euthanasia and assisted suicide (EAS) become legalized in more countries, conscientious objection (CO) by healthcare professionals is gaining increasing attention. While some argue that CO protects professionals' moral integrity, others view it as a barrier to patients' access to desired

healthcare. This review provides a comprehensive synthesis of the ethical literature regarding CO to EAS and answers three key questions: What is the meaning of CO and how is it used in EAS? What ethical positions support or challenge it? What underlying presuppositions shape the debate? Methods: We used the PRISMA guidelines, RESERVE standards, and TARCiS statement to conduct a systematic review of argument-based publications retrieved from 13 major databases covering biomedical, philosophical, and theological literature. No date or language restrictions were applied. Titles and abstracts were independently screened by the two authors, and complete articles were selected based on predefined inclusion and exclusion criteria. Results: We identified 58 relevant articles, 51 of which were published in the last decade, between 2015 and 2024. Our findings highlight three key dimensions. First, there is broad agreement on the definition of CO as the refusal to participate in a lawful medical service based on reasons of conscience. However, its interpretation and application within the context of EAS remain highly contested. Second, the ethical debate revolves around three principal positions: conscience absolutism, the compromise approach, and the incompatibility thesis. Each position is supported by distinct ethical arguments that we examine in turn. Third, the debate is shaped by several underlying presuppositions, including divergent views on conscience, morality, religion, medicine, and end-of-life care. Until these underlying presuppositions are addressed, debates on policies and practical procedures will likely remain unproductive. Conclusions: Our findings highlight the risk of polarization in the CO debate within EAS. Confrontational language often obscures shared concerns, such as respect for both professionals' moral integrity and patients' autonomy. Greater dialogue between theoretical and context-sensitive perspectives is essential for the effective implementation of CO. Clearer guidelines are needed to balance respect for conscience, patient rights, and professional responsibilities in this complex issue.

Rachel Davies

Title: “If we had known she would die here we would have stayed at home”: Clinical decision-making about hospital admission in the last year of life.

Abstract: Introduction: Unplanned admissions to hospital in the final year of life are common but may lead to physical and / or psychological harm. It is very hard to prospectively identify patients who will gain a net benefit from an admission to hospital, just as it can be very hard to prospectively identify those who actually are in their final year of life. This is even more challenging in the presence of frailty and multimorbidity. If people are made aware that they are approaching the end of life they can make their wishes for their care known, and prioritise how they spend their time according to their personal values. Unfortunately, candid conversations with clinicians are often lacking. Empirical evidence suggests that there is variation in the way that clinicians approach decisions of this nature. This empirical ethics study, which is work in progress for my PhD, attempts to add to the conversation by exploring how clinicians consider these decisions, paying particular attention to their ethical reasoning. I attempt to answer the two part question “How do, and how should, primary care clinicians approach decisions regarding hospital admission for people who may be near the end of their lives?” This presentation will share the initial qualitative results and address the first part of this question. Methods: I have carried out participant observation, with other ethnographic methods, with UK primary care clinicians over a six month period. This fieldwork took place in settings where hospital admission decisions, and related work, happened frequently. I am using reflexive thematic analysis to process the data. To address the normative aspect of my question I will be using the method of reflexive balancing to build a discussion and recommendation of how these decisions ought to be approached. Anticipated Results: I will present the main themes from my qualitative data. Discussion: Decisions of this nature are common, often occurring unconsciously where patients and clinicians may be unaware of their potential gravity. This project is exploring the reality of current practice to consider where improvements could be made to this type of end of life decision.

Nuria Terribas

Title: The experience of euthanasia in Spain: figures and difficulties of application

Abstract: On June 25, 2021, Organic Law 3/2021 regulating Euthanasia entered into force in Spain. This regulation places Spain as the fourth European country to decriminalize euthanasia and assisted suicide, and the first one to do so with a prior control system to its implementation by a Commission for the Guarantee and Evaluation. The legislator's will be to give guarantees to the citizen that the established requirements would always be met and that the authorization for euthanasia would have a prior and not subsequent supervision, as it happens in the Netherlands, Belgium or Luxembourg. The requirements to access euthanasia or assisted suicide are: to be a Spanish citizen, at least 18 years old, to request it with full capacity for 2 times with an interval of 15 days or in a document of advance directives, and to be in a situation of serious advanced illness with great physical or mental suffering or in a situation of serious suffering, chronic and disabling that entails severe limitations of daily life and without the possibility of improvement. The control of the Commission has been established with territorial scope so that each autonomous government has its own commission that must review and authorize or deny case by case, after a report from 2 doctors. This procedure slows down the process but gives it greater legal certainty. From the Commission of Catalonia, of which I am part as a senior jurist, we have already a very rich experience, having reviewed more than 850 applications. But, after four years of application, the situation is very diverse in the different territories of Spain, generating great inequality for Spanish citizens. Ideological and political aspects influence the activity of professionals and the Commissions, generating blocking and paralysis of files, to the detriment of patients who do not see their requests met. This communication presents the results of the 2023 Annual Report of the Ministry of Health as well as the detail of the activity of the Commission of Guarantees of Catalonia, which presents higher figures in 2024. Also, in these firsts' years, difficulties have appeared in interpreting the law according to the cases: mental health diseases, chronicity and old age suffering, value of advanced directives, etc., that we are trying to solve case by case.

David Lorenzo

Title: Can 'life fatigue' justify a request for euthanasia

Abstract: In recent years, euthanasia has been decriminalized or legalized in several countries. The debate on whether to legalize such a practice is open in many places and is a topic that arouses great controversy. Euthanasia has been presented as a response to situations of advanced, incurable, or irreversible disease, or situations that cause intolerable suffering to the person. However, in recent years, the claim has been asserted that this practice does not have to be associated with such situations. It may happen that a person wants to die and asks for help to do so, even if they are not in a specific clinical situation (pathology or condition) but are experiencing advanced age or present 'vital fatigue'. The objective of this communication is to critically analyse the concept 'vital fatigue': to define its meaning, its characteristics, its causes, and its consequences in the debate around euthanasia. This analysis is based on a critical review of the main discussions and arguments present in the literature. It is concluded that vital fatigue can be understood as a product or manifestation of an individualistic and productivistic vision of the human being, in which its relational nature and intrinsic value remain in the background. The loss of the meaning of life also influences it. Therefore, in the face of this phenomenon, the most guaranteeing and ethical option is −we believe−accompaniment and holistic care of the person that allows the causal factors to be modulated, without the need to resort to euthanasia.

Ethical Spaces in Intersex and Gender-Affirming Care (AFL-E-019)

Martin Gramc

Title: What Care for Intersex and Transgender People?

Abstract: Over the past decade, many countries in Europe and the USA improved gender affriming care for youth and introduced new models of care for intersex children and adolescents. Changes in health care have been accompanied by new legal approaches as growing number of Europian coutries banned medically unnecessary interventions on intersex children, while many others have abolished sterilisation requirements for legal gender recognition and, at times, introduded self-determination models. However, recent political changes in the USA took a negative turn as the executive orders by President Trump canceled access to care for transgender youth which seems to impact the delivery of care for intersex children and adolescents. Against this background, this presentation pursues two interconnected aims. First, it argues that despite the positive developments, most European jurisdictions do not take access to adequate healthcare of intersex and transgender people seriously enough. It is as if recognising the rights of trans and intersex people ends at preserving their physical integrity by abstaining from intervening on their bodies, thus endorsing a limited vision of what justice might mean for them. Second, considering the lastest political developments in the USA targeting gender affirmative care this presentation explores the intersection of intersex and transgender healthcare, focusing specifically on legal approaches to care for children and adolescents in USA, Germany, and Malta. This exploration highlights how the absence of robust legal frameworks for healthcare access shapes the personal experiences of ‘autonomy’ and ‘care’ for intersex and transgender youth.

Eva De Clercq

Title: Building Expertise in Healthcare Navigation Supporting Families and Patients with Variations of Sex Characteristics

Abstract: Variations of Sex Characteristics (VSC), affecting approximately 0.05% to 1.7% of infants, involve differences at the chromosomal, anatomical, or gonadal level that do not fit into the male-female binary. While the 2006 Consensus Statement on the Management of Intersex Disorders was a pivotal development in the care of individuals with VSC, it has been criticized for reinforcing shame, stigma, and harmful medical practices. In 2012, the Swiss National Advisory Commission on Biomedical Ethics recommended delaying medically unnecessary surgeries with irreversible consequences and proposed legal sanctions for such procedures. Yet, in 2023, despite acknowledging the need for better protection of children with VSC, the Swiss Federal Council chose not to criminalize these surgeries. This highlights the ongoing complexity and contention surrounding medical and surgical approaches to VSC and the ethics of decision-making in this area. Relying solely on legal restrictions is insufficient to guarantee the delivery of high-quality, person-centered healthcare. Shared decision-making (SDM) is widely regarded as essential in promoting collaborative decision-making between patients, families, and healthcare professionals. However, implementing SDM effectively in healthcare settings remains challenging. Families and individuals with VSC face a range of intricate choices, from decisions about gender of rearing to surgical interventions, mental health care, transitional services, and family-building options. To better support SDM in the care of those with VSC, we propose the integration of decision coaching—a non-directive, relational approach facilitated by a trained healthcare provider. In collaboration with the Institute of Public Health and Varia Suisse, the Gesundheitskompass foundation plans to train approximately 10 healthcare navigators across Switzerland. These navigators will be equipped with expertise in SDM principles and VSC-specific health concerns. This presentation will present a sustainable model for training healthcare navigators to enhance the care experience for individuals with VSC.

Bijosh Moolekkudiyil Baby

Title: Gender Reassignment Surgery as a Treatment Option for Gender Dysphoria in Adults: A Review of Ethical Reasons

Abstract: Background: Gender dysphoria, as defined in the DSM-5-TR, is the psychological distress experienced by some people whose sex assigned at birth differs from their perceived gender identity. The distress leads to an intense desire and attempt to change their physical sex organs to match their perceived gender identity. The prevalence of reported cases of gender dysphoria has been increasing globally in recent years. Gender reassignment surgery (GRS) is widely practiced and promoted as a promising treatment option for gender dysphoria. However, it is important to note that these surgical interventions are not ethically neutral, even when adopted by adult individuals. Despite the widespread practice and promotion of GRS, the scientific literature lacks comprehensive systematic reviews addressing the ethical dimensions surrounding GRS as a treatment option for gender dysphoria. Methodology: We conducted a systematic review of reasons following the framework proposed by Strech and Sofaer, 2012 to identify and analyse all ethical reasons in the normative ethics literature related to GRS as a treatment option for gender dysphoria. The literature search was conducted in seven relevant major online databases in addition to the Google Scholar search engine. Results: Our literature search identified a total of 29 articles published in English between 2003 and 2023 that discussed the ethical dimensions of GRS as a treatment option for gender dysphoria in adults. The reasons identified in the literature were classified into five major categories namely, reasons related to the origin and nature of gender dysphoria, reasons related to GRS as a treatment for gender dysphoria, anthropological reasons, reasons related to the effects of GRS, and reasons stemming from traditional ethical principles. Discussion: By mapping and analyzing a wide range of ethical reasons, both for and against GRS, this review highlights the ethical complexities inherent in the debate surrounding GRS in adult individuals. It also identifies certain areas of ambiguity that require further exploration to reach a meaningful ethical conclusion on GRS as a treatment option for gender dysphoria in adult individuals. Highlighting the intense psychological distress of the people as a key consideration for further ethical reflections, this review underscores the importance of integrating insights from empirical research to enrich the future ethical deliberations on the topic.

Rethinking Animal Research in a One Health Framework (AFL-E-019)

Selina Wegmüller

Title: An analysis of ethical arguments in the public debate on animal testing in Switzerland

Abstract: The regulation of animal research remains a topic of frequent debate in Switzerland. Since the 1980s, various popular initiatives have emerged, proposing stricter regulations such as a complete ban on animal experimentation. Each associated referendum has generated a public discourse on animal research, involving various ethical arguments and reflecting shifting sentiments of the population. Our research examines the ethical dimensions of the societal debate on animal testing in Switzerland over time. Through a qualitative content analysis, we analyse the key ethical arguments for and against animal testing, utilising data from VOX analyses, which document national voting decisions in post-vote surveys on behalf of the Federal Council since 1977. By reconstructing the dialectical structure of the debate based on Betz's framework (2010), we aim to identify which arguments recur in the four votes on the ban of animal testing and which are structurally stronger or weaker. This approach enables us to establish a hierarchy of reasons and the dialectical relations between arguments using philosophical methods. To visualise these findings, we employ the Argument software developed by Betz et al. The main arguments in favour of animal testing are primarily economic, while the main arguments against it are mainly ethical. The economic considerations are based on the need to safeguard Switzerland as a location for science, preserve jobs, avoid dependence on foreign countries, and regard animal testing as necessary for personal safety and well-being of humans. The moral concerns, on the other hand, are mainly based on the argument that animal testing is ethically unacceptable as they fail to protect animals and their right to physical and psychological integrity and that there are sufficient alternative methods, which are more effective, making animal testing

no longer necessary. Based on this, we will analyse which arguments have been particularly recurring over the years and whether they are consistent in their argumentative structure. To share this knowledge, we will create an interactive website that makes our results accessible to everyone interested and will provide the various stakeholders and the public with the means to use more solid arguments instead of moral intuitions without an argumentative basis. The interactive website will serve as a lasting resource for the public and can also be integrated into educational activities at universities and schools.

Yesim Isil Ulman

Title: Reimagining the Three Rs in the Era of One Health: A Qualitative Research on Early Career Science Researchers

Abstract: The progress of science is needed for the health of humans and animals, environmental sustainability, and the well-being of society. Laboratory animals are crucial for scientific studies, contributing to educational and scientific advancements. Over the past decade, as the One Health concept has gained traction in policy, practice, and research, this holistic perspective has required a reevaluation of traditional research paradigms, including the application of the 3 Rs (Replacement, Reduction, Refinement). Decisions on biomedical studies involving animals should be made by considering the welfare of the animals used, and they should be based on scientific knowledge and professional competence. This study aims to explore how the 3 Rs advocate for animal research and how the One Health approach applies to studies involving laboratory animals, while also investigating researchers' awareness and attitudes, particularly their recognition of animals as living and sentient beings. It investigates the values they invoke to justify research and experimentation on animals (Values) and examines their knowledge of alternative methods that could replace animal use (Replacement). Additionally, it seeks to understand the challenges they face in determining, calculating, and minimizing the number of animals in their studies (Reduction), as well as their perspectives on ensuring the welfare of animals housed in laboratory conditions (Refinement). The research further delves into their experiences with the ethical approval process, from project preparation to submission and evaluation by Ethics Committees (Ethical Process). Finally, it examines how researchers perceive the interconnections between human, animal, and environmental health, and how this perspective shapes their research practices (One Health). This qualitative study will employ in-depth, semi-structured interviews with early career science researchers, complemented by participant observations during laboratory work. The collected data will be systematically analyzed using qualitative analysis software. This study explores the awareness, opinions, and experiences of researchers regarding the 3 Rs & One Health. By critically examining harm-benefit analysis through ethical responsibility from an interdisciplinary perspective, this study aims to enhance practices in animal research and welfare by incorporating bioethical principles that uphold respect for biodiversity, the biosphere and the concepts of One Health.