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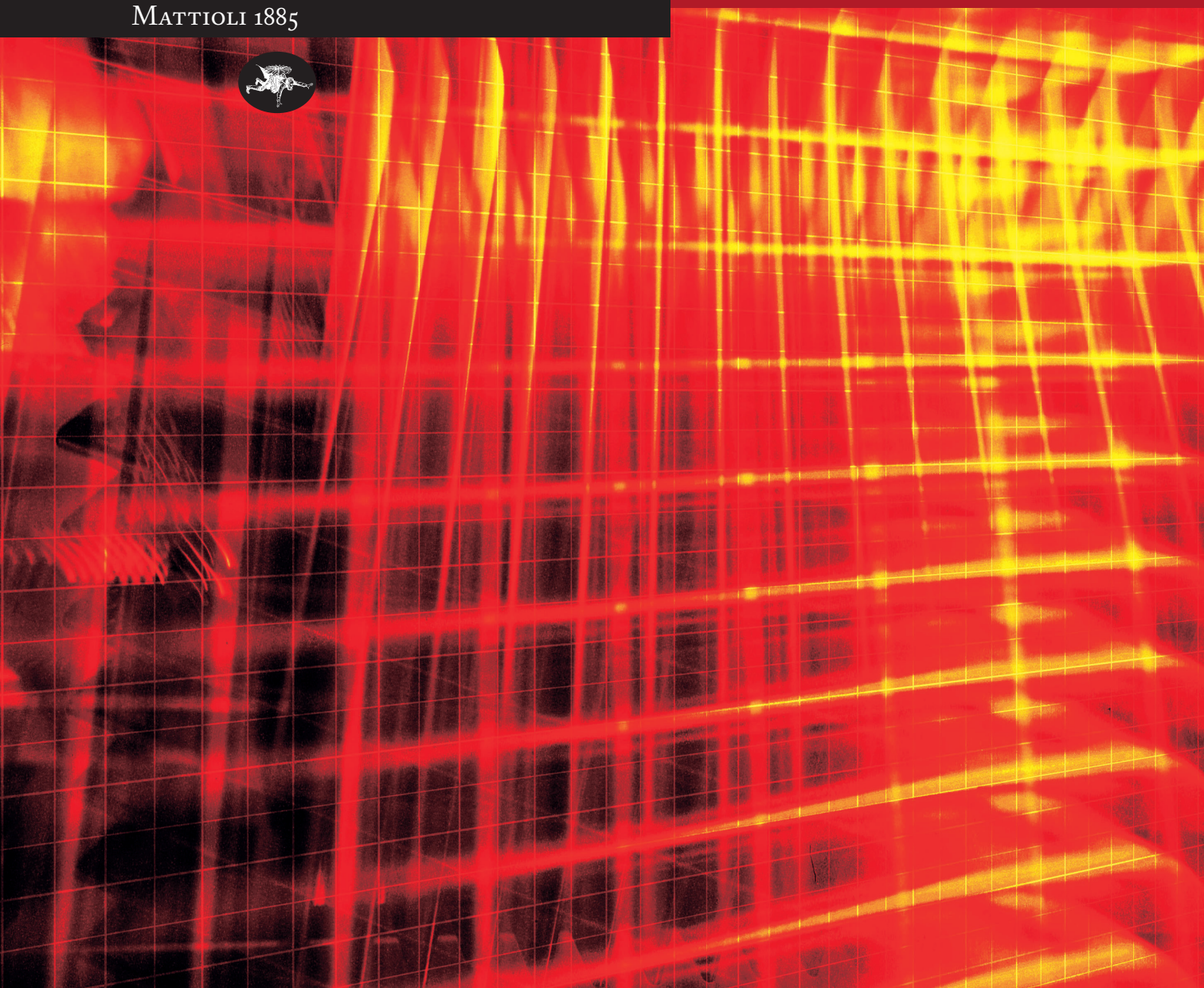
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Enhancing dialogue to bridge the gaps in Bioethics - Abstract Book

Editors: Federico Nicoli, Elena Ferioli, Alessandra A. Grossi, Mario Picozzi

EACME Annual Conference 2022 - Varese, 15-17 September 2022

Mattioli 1885



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DIPARTIMENTO DI BIOTECNOLOGIE E SCIENZE DELLA VITA – DBSV
Centro di Ricerca in Etica Clinica (CREC)

EACME
EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

EACME ANNUAL CONFERENCE 2022

Varese, 15 - 17 September 2022

ENHANCING DIALOGUE
TO BRIDGE THE GAPS IN
BIOETHICS

ABSTRACT BOOK

Nicoli F, Ferioli E, Grossi AA, Picozzi M
(*Editors*)

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About the Editors



Federico Nicoli (MA, PhD) is a Clinical Ethicist. He is a member of the Scientific Committee of the Center for Clinical Ethics, University of Insubria, Varese (Italy) and the responsible of the Clinical Ethics Service at Domus Salutis Clinic in Brescia (Italy). He is a member of the EACME Bureau in the role of treasurer (2020-2024). His research focuses on clinical ethics, clinical ethics consultation and end of life.



Elena Ferioli (Molecular Biologist, PhD) is Coordinator and Scientific Secretary of the Center for Clinical Ethics at the University of Insubria, Varese (Italy). His research focuses on bioethics, with a particular interest in Biobank ethics consultation, GenEthics, Human Enhancement and ethics of Biotechnology medicine.



Alessandra A. Grossi (MSc, MAS, PhD) is a Health Communication and Medical Ethics specialist, a Post-Doc research fellow, and an active member and research collaborator of the Center for Clinical Ethics at the University of Insubria, Varese (Italy). Her research focuses on clinical and public communication processes, health disparities, diversity in healthcare, and person- and family-centered care.



Mario Picozzi (MD, PhD) is Associate Professor of Legal Medicine and Director of the Center for Clinical Ethics at the University of Insubria, Varese (Italy). His research focuses on clinical ethics, with a particular emphasis on clinical ethics consultation, beginning and end-of-life issues and organ transplantation

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Enhancing dialogue to bridge the gaps in Bioethics
EACME annual conference 2022

Federico Nicoli, Elena Ferioli, Alessandra A. Grossi, Mario Picozzi (Editors)

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Since its foundation in 2016, the Research Center for Clinical Ethics (CREC) promotes the study of bioethics and clinical ethics, through research, training and consultancy activities in the university and hospital environment. Over these five years, the center has become a national landmark for the study of ethical issues in medicine. CREC is one of the promoters of the PhD Program in Clinical and Experimental Medicine and Medical Humanities, University of Insubria, and – within this doctoral program – it is responsible for the Medicine and Human Sciences track.

For further information, please visit our website: http://crec.uninsubria.it



About the European Association of Centers of Medical Ethics (EACME)

EACME, was founded in the early 1980s by a small group of theologians, philosophers and medical doctors who were involved in the new discipline of medical ethics or, as it is now often called, bioethics. These so-called 'founding fathers', had the intention to create a network of centres of medical ethics in Europe with the purpose to strengthen the teaching, research, communication and debate on ethical issues in medical practice, health policy and medical sciences. The official starting date of EACME is the 2nd of December 1986 when representatives of six centres came together in Lyon to create this new organisation. The centres (including the Bulletin of Medical Ethics) were located in France (Lyon, Paris), Spain (Barcelona), Belgium (Brussels), the Netherlands (Maastricht) and the United Kingdom (London). The strong presence of clergymen on the original Board was the reason the EACME has stressed from the start its pluralist approach to bioethical issues. The association expanded in the nineties, when bioethics centres in Europe were increasingly cooperating in research and teaching projects funded by the European Commission. This development was the background for the professionalisation of the young association, strengthened by an efficient organisation and administration under the guidance of the EACME Board and Bureau. New centres joined the organisation, from all over the European continent, stimulating and strengthening the pluralist character of EACME.

Currently, about 60 centres are members of EACME, including associate members. The most important activity of EACME is the Annual Conference, organised by one of its members with support by the members of the Bureau. The conference presents an open platform for research contributions and debate about ethical issues in health care practices, policies, and biomedical sciences as well as new approaches in clinical ethics, research ethics and ethics teaching.

While in the early days EACME conferences were in general meetings for senior bioethicists, the current annual conferences of EACME are offering opportunities for both senior and junior researchers to present their work to a broad international audience. The EACME specifically encourages collaboration between its member centres and offers an Exchange Programme and Collaboration Prize. To conclude, EACME has developed from a relatively closed meeting space for pioneer bioethicists towards an open and vibrant community for senior and junior researchers with the aim to develop and strengthen the discipline of bioethics in the European context.

For further information about EACME and the advantages of EACME membership, please visit: www.eacmeweb.com



Program: Enhancing Dialogue to Bridge - The Gaps in Bioethics

Fifty years after the publication of the well-known 1971 book *Bioethics: Bridge to the Future* by Van Rensselaer Potter, and the foundation of the Kennedy Institute of Ethics, the main aim of the 38th EACME Annual Conference in Varese (Italy) is to reflect upon the theme of dialogue as a bridge to overriding gaps in bioethics. Such gaps are even more evident after the Covid-19 pandemic. The emergency has underlined the great need for bioethical reflections, yet at the same time it has highlighted how difficult it is for bioethicists to significantly affect the public debate. In other words, bioethics has not been as *effective* as we would have liked. These aspects prompt us to reflect on the very roots of our field, facing both old and new challenges. We have singled out four main topics:

a) *The dialogue **on** bioethics*: on the basis of what we have just said, with this topic we would like to attract general reflections on theories and methodologies in bioethics, the role of bioethics in our pluralistic society, and the different approaches in bioethics. We also included the sub-topic "Bioethics education" to reflect not only on education for health care workers, but also on the need to raise awareness regarding bioethical issues.
b) *The dialogue **in** clinical practice*: the host center for EACME 2020 has always been interested in addressing ethical issues in clinical practice. With this topic, we would like to attract papers which stress the importance of relationships in care practice and which address ethical issues in all the several sub-themes reported.
c) *The dialogue **with** society and politics*: if we want bioethical reflection to influence public opinion, we also need to address the fascinating issue of the relationship with society and politics. We would therefore, like to attract papers concerning fairness and justice in health care, the role of mass media and social media
d) *The dialogue **towards** the future: new and emerging technologies*. With this topic, we want to attract papers that investigate the ethical issues arising from the implementation of new technologies in medicine.

General Topics and Sub Themes

1. The dialogue *on* bioethics - The relevance of theories and methodologies in medical ethics - Rethinking the role of bioethics after Covid-19 - Religious and cultural pluralism in bioethics - Education and Awareness of healthcare professionals about bioethical issues - Beyond medical ethics: animals and environmental ethics	**2. The dialogue *in* clinical practice** - Scope and limits of autonomy in clinical practice - Different methods in clinical ethics consultation - Ethics in organ transplantation - The influence of a clinical ethics service on moral distress - Ethics and the blurred line between clinical practice and research
3. The dialogue *with* society and politics - The dialogue between ethics, deontology and law - The role of bioethics in national and international political decisions - Justice, solidarity, and equity in health care - Public opinion and media - Global bioethics and local bioethics	**4. The dialogue *towards* the future: new and emerging technologies** - Gen-Ethics: Genetic tests, Gene Therapy, Biobank - Robo-Ethics, Nano-ethics, Public Health 4.0 and High-Tech Medicine - Neuro-Ethics: Neurolaw, cognitive sciences, free will and moral cognition - Digital medicine: big data, and privacy - Bio-security and biological threats

Overall Program*

EACME Annual Conference 2022 - Enhancing dialogue to bridge gaps in bioethics (September 15-17, 2022)			
Time	**Thursday, September 15**	**Friday, September 16**	**Saturday, September 17**
Venue	Municipality of Varese (Via Luigi Sacco 5, 21100 Varese)	Via Monte Generoso 71, 21100 Varese and TM/PM Rooms (Padiglione Morselli - 5' walk from MTG Building)	Via Monte Generoso 71, 21100 Varese
8.30		**Registration**	**Registration**
8.45		**Paul Schotsmans PhD Prize**	
9.00		**Plenary Session 2: The dialogue in clinical practice (Room 12MTG)** Chair: Federico Nicoli **Key lecture: Gerald Neitzke** Discussants: Massimo Cardillo Veronique Fournier and Nicolas Foureur	**Plenary Session 4: The dialogue towards the future: new and emerging technologies (Room 6 MTG) Round Table** Chair: Giovanni Bernardini Discussants: Davide Battisti Marianne Boenink Massimo Reichlin
9.15			
9.30	**Board of directors EACME**		
9.45			
10.00			
10.15			
10.30			
10.45		**Coffee Break**	**Coffee Break**
11.00			
11.15		**Parallel Sessions II**	**Parallel Sessions IV**
11.30			
11.45			
12.00			
12.15			
12.30			
12.45			
13.00		**Lunch Meeting/Lunch Break**	**Closing Session & EACME 2023 Announcement (Room 6 MTG)**
13.15	**Registration**		
13.30			
13.45			
14.00			
14.15	**Opening Session**	**Plenary Session 3: The dialogue with society and politics (Room 6 MTG)** Chair: Alessandra A. Grossi **Key lecture: Ana Borovecki Nicola Magrini**	
14.30			
14.45	**Plenary session 1: The dialogue on bioethics (Salone Estense)** Chair: Renzo Pegoraro **Key lecture: Laura Palazzani**		
15.00			
15.15			
15.30			
15.45		**Coffee Break**	
16.00			
16.15	**Break**	**Parallel Sessions III and Poster carousel**	
16.30			
16.45	**Parallel Sessions I**		
17.00			
17.15			
17.30			
17.45			
18.00		**General Assembly EACME (Room 6MTG)**	
18.15			
18.30	**Welcome Cocktail** Estensi Gardens (https://www.comune.varese.it/hh/index.php)		
18.45			
19.00			
19.15			
19.30			
19.45			
20.00			
20.15		**Conference Dinner** Palace Grand Hotel **(https://varese.ipalazzihotels.com/)**	
20.30			
20.45			
21.00			

*For additional details of key lecturers and/or discussants, please see dedicated sections of the abstract book.

Introductory greetings

Dear friends and colleagues,

This year's EACME Annual Conference is the first fully in-person meeting since the start of the Covid pandemic in 2020. As much as we may have learned to value the possibility to meet virtually or to host hybrid meetings, personal encounters are unbeatable. This is even more important if we want to reflect upon the ***"Dialogue to bridge potential gaps in bioethics"****. On behalf of the EACME Bureau, I would like to thank Mario Picozzi and his team at the University of Insubria, for having chosen such a topical theme for this conference. This choice was inspired by Van Rensselaer Potter's book "Bioethics: Bridge to the Future" published in 1971, at a time of growing awareness of the need to integrate ethics - right from the start - into the development of new scientific discoveries. Although we have possibly reached the future Potter referred to at the time, and we see ethics expertise often embedded in scientific projects, the need for strong collaborations between ethics and science, and in particular, the discussion about best practice for this, is still very much present today. We all look forward to the opportunity this conference provides to discuss how ethics and biomedical science as well as its clinical implementation can best work together, and how dialogue between ethics, science and society can be enhanced.*
Many thanks to everyone for being here with us in Varese, and who participates in and contributes to our fruitful discussions. Thanks again to the whole Varese conference team for their hospitality and this promising conference.
A warm welcome to you also from the EACME Bureau,

Ruth Horn
President of the EACME
Varese, 15th September 2022

Dear friends,

When launching this Conference, we wrote:
Fifty years after the publication of the book Bioethics: Bridge to the Future by Potter, and the foundation of the Kennedy Institute of Ethics, the main aim of the 38th EACME Annual Conference is to reflect upon the theme of ***DIALOGUE AS A BRIDGE TO OVERRIDING GAPS IN BIOETHICS.***
Such gaps have become more and more evident after the COVID-19 pandemic.
This prompts us to reflect on the very roots of our field, facing both old and new challenges, represented by the four main topics of this Congress:
a) The dialogue ***on*** *bioethics*
b) The dialogue ***in*** *clinical practice*
c) The dialogue ***with*** *society and politics*
d) The dialogue ***towards*** *the future*
Starting from different visions, cultures and competences, ***dialogue is the ability of men and women who keep wondering about all questions of life and have in common the research of that good that authorizes the commitment of freedom.***
This is the challenge we want to take up these 3 days, during the general sessions, the 150 speeches and 17 posters. We can finally attend this Conference in person, side by side! We will spend these days here, in Varese, in the dialogue represented between the two venues of the conference, between the city and the University, between the home of civil institution and the home of research and education, while recognizing that within our own roles we need a mutual contamination.
Dear friends, welcome to Varese!

Prof. Mario Picozzi
President of the Conference
Director Center for Clinical Ethics, Insubria University

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Thursday, September 15th, 2022
Plenary Session 1: The dialogue on bioethics

Chair: Renzo Pegoraro - Key lecture: Laura Palazzani



Professor **Laura Palazzani** graduated with a Degree in Philosophy at the Catholic University of the Sacred Heart in Milan in 1989; in 1991 she was Visiting Researcher in Biomedical Ethics (Georgetown University, Washington D.C.); in 1992/1996 she obtained a Ph.D. in bioethics at the Catholic University of the Sacred Heart in Rome. In 2004 She became Full Professor of Philosophy of law at LUMSA University, Rome. She was appointed member of the Italian Committee of Bioethics (2002-2007); and subsequently vice-chair (2008-2022). She is a member of the UNESCO International Bioethics Committee and official Italian delegate to the Committee on Bioethics DH-BIO, Council of Europe. She has recently been reappointed for a third mandate member of the European Group on Ethics in Science and New Technologies, European Commission. She is ordinary member of the Pontifical Academy for Life and member of the Ethics Committee of the Bambino Gesù Children's Hospital of Rome. She has published 18 books, more than 300 articles both in Italian and other languages. Among the books: *Bioethics and biolaw: theories and questions*, Giappichelli, Torino 2018 *Innovation in scientific research and emerging technologies*: *governance*, Giappichelli-Springer, 2019. Fields of research and publications: beginning and end of life issues, clinical trials, informed consent, emerging technologies, philosophy of law and biolaw, gender theories, family

Abstract:

Since the birth of the term bioethics, V. R Potter has referred to a 'bridge' between two cultures, scientific culture and humanistic culture. Bioethics begun to question the relationship between tecno-scientific possibility and ethical legitimacy, demanding a dialogue between scientists and ethicists.

The development of bioethics since the beginning has been strongly marked by ethical pluralism. Each philosophical perspective conceives 'dialogue' in a different way. The liberal-libertarian perspective considers dialogue as a negotiation procedure, in order to resolve bioethical controversies between 'moral strangers'. Utilitarian bioethics identifies dialogue as an agreed calculation, on a collective level, of the maximization of benefits and minimization of sufference for the greatest number. Personalism, in a cognitivist perspective open to the progressive knowability of objective truth, considers dialogue as the recognition of the dignity of each human being, which has the ontological relational possibility to communicate, to understand the moral duty to respect the other, according to justice as giving each his/her own.

Bioethics Committees play a key role, both at national, regional and international levels, engaging in dialogue, considering both interdisciplinarity and pluralism. The reason why Bioethics Committees have been established is

an increasing need for dialogue in order to identify (if possible) an 'ethical mediation', which should not be reduced to a mere compromise or pragmatic agreement, but as a minimum level (or maximum possible level) of shared ethical principles/values on specific topics.

The elaboration of minimum ethical elements for regulating techno-science draws inspiration from the horizon of fundamental human rights as a conceptual framework, which form a crucial part of national constitutions and international documents. These documents have undergone, in recent decades, a process of explicit specification and interpretation, in light of emerging issues stemming from scientific and technological development. The universalistic claim of human rights has facilitated the formulation of intercultural and transcultural standards.

In the context of ethical pluralism, there is an increasing need for shared ethical values and principles, in the face of the complexity of scientific and technological advancement, through balanced critical reflection and dialectic argumentation, focusing on the primacy of the human being over the sole interest of science or society; the protection of freedom, in both the sense of autonomy and responsibility, especially with regard to those who are facing inability or particularly vulnerable conditions; justice or guaranteeing equal treatment for all, equity of access to healthcare, equality, non-discrimination and solidarity; and caution and prudence in the face of uncertain or risky technologies that are likely to cause serious and irreversible damage to human beings, humanity, the environment and future generations

Beyond the institutionalization of Bioethics with the Committees, the role of 'active citizenship' and 'citizen participation' is growing in importance in bioethics, along with the need to build platforms for dialogue with society, which enable dynamic updating and active interaction between experts and citizens. Interaction aims to adequately inform and educate the citizens (the so called 'bioethics literacy'), in order to raise social awareness, in order to ensure their democratic participation, public engagement and active involvement in ethical reflections on tecno-scientific development. Through pandemics we have achieved awareness about the relatedness and interconnectedness of all individuals and the need for common values in bioethics, the need of a dialogue in the framework of human rights.



Abstract Book

Parallel Session 1
Room: Salone Estense
Chair: Rouven Porz

(1) Title: Putting ICU triage guidelines into practice: a simulation study

Authors: Inger Abma PhD, postdoc researcher; Gert Olthuis PhD, senior researcher; Anke Oerlemans PhD, senior researcher - IQ healthcare, section Ethics of healthcare, Radboud Institute of Health Sciences, Radboud University Medical Center, the Netherlands

Abstract:
Background: The COVID-19 pandemic has prompted countries to formulate guidelines on how to deal with a worst-case scenario in which more patients need intensive care than there are available beds. This study aimed to explore the experiences of triage teams when triaging fictional patients with the Dutch triage guidelines. Like international guidelines, these guidelines are mainly based on the principle of "maximizing benefits". The study provides insight into the acceptability and applicability of the guidelines and gives an overview of the factors that influence decision-making when performing intensive care triage with guidelines.
Methods: Eight triage teams from four hospitals were presented with files of fictional patients needing intensive care treatment and instructed to triage these patients like they would during a crisis. Sessions were observed and audio-recorded. Four focus group interviews with triage team members were held to reflect on the sessions and guidelines. The results were analyzed by inductive content analysis.
Results: Triage teams generally considered the Dutch triage guidelines acceptable and feasible and they were the main basis for triage decisions. Some teams allowed their own considerations to weigh in when making triage decisions, for example to avoid having to use non-medical criteria such as age group. Group processes also played a role: triage choices can be influenced by the triagists' opinion on the guidelines and the carefulness with which they are applied. Intensivists had the most relevant experience for making medical estimations such as a patient's prognosis, meaning they often had the largest role during triage sessions.
Conclusions: Using the Dutch triage guidelines is feasible, but there were some inconsistencies in prioritization between teams that may be undesirable. Triage guideline writers should consider which aspects of their criteria might, when applied in practice, lead to inconsistencies or ethically questionable prioritization of patients. Offering triage team members training in which the reasoning for the criteria is explained, and in which they can practice applying the guidelines, might improve both the willingness and ability of triage teams to follow the guidelines closely. Furthermore, triage team members may experience moral distress while performing triage: they should be offered psychological support.

(2) Title: Italians' opinions on lockdown and intensive care allocation

Authors: Mirko Ancillotti, PhD, Uppsala University, Sweden; Virginia Romano, PhD, Eurac Research, Italy; Deborah Mascalzoni, PhD, Eurac Research, Italy; Roberta Biasiotto, PhD, University of Modena and Reggio Emilia, Italy

Abstract:
Year 2020 started with the widespread diffusion of SARS-CoV-2. Italy was heavily affected and the government enforced a national lockdown from March 9th to May 18th, 2020. In order to explore the impact of public health measures on people's life and their views on such measures, we carried out 18 online interviews with lay people in April-June 2020. We analyzed the interviews through qualitative content analysis.
The lockdown affected people's life resulting in a need for substantial modifications in daily activities and reconsideration of personal relationships. These changes entailed both positive and negative aspects, and were met with resilience. Media were confusing, leading to a renewed critical attitude toward information news. Even if restriction of movement measures were considered adequate and compliance was equated to responsible behavior, they generated uncertainty and stress, and revealed tensions and inequalities within society. Respondents struggled when tased with imagining a scenario with saturated intensive care units (ICUs) and the ensuing need for prioritization. The issue was readily interpreted as an ethical dilemma and not merely as a medical one. Although concerns were voiced about who should make such life-or-death decisions, respondents held the view that its solution should ultimately be resolved by healthcare professionals. On March 6th, 2020, the Italian Society of Anesthesia, Analgesia, Resuscitation and Intensive Care (SIAARTI) issued recommendations and ethical considerations for the care of critically ill COVID-19 patients in scarce resources settings. Respondents' opinions and SIAARTI's recommendations converged on the notion that age is a decisive criterion, but on different grounds. The former applied a kind of fair innings argument, i.e., that there is some span of years that is reasonable for a person to have lived and, under severe circumstances, the younger should be prioritized. SIAARTI's recommendation was instead justified by a maximization principle based on medical considerations.
Gaining insights into public response, including moral reasoning, about restrictive public health measures is valuable for public health and emergency preparedness in health emergencies. Lay people's propensity to assign a normative and/or regulatory value to medicine and its experts is worth being further investigated and discussed.

(3) Title: Decisions to withhold and withdraw treatment in ICUs and the deliberation process: clinical ethics and the critique of consensus.

Authors: Marta Spranzi, Associate professor, University of Versailles St-Quentin, medical school; ethics consultant, Center for clinical ethics (AP-HP, Paris)

Abstract:
According to French law (Art. R. 4127-37-2.-I) decisions to withhold and withdraw treatment for incompetent patients have to be preceded by a "collegial procedure", that is a deliberation process during which a certain number of designated participants (physician in charge of the patient, nurse representative, external consultant) discuss the patient's situation, her chances of being discharged alive, and to recover with an acceptable quality of life. The deliberation process also indirectly includes the views expressed in advance directives if they are available, and the opinion of a "trusted person", if possible designated by the patient herself. How should such deliberative meetings be organized, in order to maximize the chances that the decision made following the collegial procedure is ethically appropriate? In intensive care units, the achievement of consensus is most often considered to be the hallmark of an ethically justified decision. But is it the right approach? Drawing on the results of a clinical ethics

empirical study in 7 intensive care departments within the Paris greater hospital trust, I will discuss advantages and drawbacks of the consensus approach, as they have been described by intensivists themselves. I shall conclude in a rather counterintuitive way by suggesting a) that participants should be given differential weight in the deliberation process, and that the physician and nurse who know the patient should have a larger role; b) that dissensus rather than consensus is a more constructive approach from an ethical point of view. This is so because it allows all the conflicting values that HCP bring to bear on the decision to be properly expressed and given pride of place. The ultimate decision should not be conceived as the direct outcome of the deliberation process, but as a difficult bet on the patient's future, and that the attending physician has to take responsibility for it after having carefully weighed all the widely different arguments put forward by participants in the deliberation process.

(4) Title: Differences in Communication Between Physician and Patient with Acute and Chronic Disease: Bioethical Perspectives

Authors: Matteo Zanetti, PhD Student in Bioethics, University of Verona

Abstract:
Communication forms an essential part of the relationship between physician and patient. Like much of medical practice today, it is based on the autonomy paradigm, where two autonomies (physician and patient) make an agreement: in exchange for temporary submission to the physician's authority, the patient obtains to recover health. It is often called the 'contractual model' of health care. The role of communication is to let the agreement begin, develop, stop, or change.
In chronic diseases, the situation is more complicated. A cure is not always possible or takes a very long time. Therefore, the terms of the agreement must be different because the chronic disease cannot be seen as an enemy that must be defeated but as an enduring component of the patient's life, with which both the physician and the patient must come to terms.
Three different types of relationships characterise the chronic condition. The first relationship is between physician and patient. The physician has limited 'power' (he can only, for example, slow the progress of the disease or manage its symptoms). He sheds the aura of Deus ex machina to become a travel companion, someone with specific know-how that can help patients live their lives in the best possible way. The second relationship is between patient and disease. Nothing can eradicate the illness, so patients must see the disease as a part of their life. They must modify their habits and everyday life to accept the disease. The third relationship is between patients and themselves. They must find a new meaning for their life that excludes the possibility of recovering 'perfect' health and any notion of total self-sufficiency and autonomy.
Because of the nature of chronic diseases, physicians become an essential presence in patients' life. Thus, the first relationship acts as the foundation of the other two. Chronic patients need physicians to face and understand their life more than acute patients. Consequently, the patients' autonomy grows within the three relationships. Chronic diseases bring out a notion of autonomy that is not a given characteristic of human nature, but it changes in time, following personal and clinical history.

(5) Title: Socio-cultural influences on provider-family relational dynamics in intensive care settings: a single-center experience during the COVID-19 pandemic in Northern Italy.

Authors: Alessandra Agnese Grossi (presenting author and point of contact), Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, University of Insubria, Varese, Italy; Alessandra Vicentini, Department of Human Sciences, Innovation and Territory, University of Insubria, Como, Italy; Daniele Grechi, Department of Economics, University of Insubria, Varese, Italy; Silvia Ceruti, Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, University of Insubria, Varese, Italy; Mario Picozzi, Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, University of Insubria, Varese, Italy

Abstract:
Quality communication is critical for patient- and family-centered care (PFCC) in intensive care units (ICU). The COVID-19 public health emergency has amplified the need to assure high-quality provider-family communication in ICUs. The inability for patients' families (PF) to access hospital facilities during the peaks of the pandemic has affected communicative practices, requiring identification of a point person (PP) within family units for remote interactions. These novel dynamics require improved understanding of the factors enabling the provision of PFCC. From a socio-ecological perspective, the way in which HCPs and PFs interact is affected by the contexts where the interactions occur. Yet, the most influential context is the interpersonal one, depending on the interactants' goals, skills, perceptions, emotions, and constraints and opportunities they respectively create. Because gender is a social construction in that specific traits, statuses, or values are attributed to individuals because of their gender, the socio-cultural context may be a determinant of PPs' gender and kinship/relationship with hospitalized patients who are unable to communicate. According to Hofstede's cultural dimensions theory, masculinity vs. femininity is related to the distribution of values between genders. With a high score on the masculinity/femininity index, Italy is a masculine society, with a high differentiation of social and emotional roles between women and men. Based on these considerations, we hypothesized that, because women in masculine societies are generally more caring, PPs within family units during COVID-19 were mostly females.
This study explores the association between patients' sociodemographic variables and PPs' gender and kinship/relationship. Data extracted from medical records archived during the second COVID-19 surge (01.09.2020-31.03.2021) have been provided by a major hospital in Northern Italy. Descriptive and inferential analyses, and statistical models will assess the relationships between variables. Data will be qualitatively interpreted according to intercultural and medical communication models, and critical discourse studies.

Parallel Session 2
Room: Sala Matrimoni
Chair: Davide Battisti

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(6) Title: Non-invasive prenatal testing in Germany: a unique ethical and policy landscape

Authors: Hilary Bowman-Smart, Research Fellow, University of Oxford; Ruth Horn, Associate Professor, University of Oxford

Abstract:
Non-invasive prenatal testing (NIPT) has been available commercially in Europe since approximately 2012. Currently, many countries are in the process of integrating NIPT into their publicly funded healthcare systems to screen for chromosomal aneuploidies such as Trisomy 21, with a variety of implementation models. In some countries, such as Belgium, NIPT is being implemented as a first-line screen (available for any pregnancy); in others, such as France, as a contingent screen (available for pregnancies with an increased probability of a chromosomal condition). However,

Germany has a model that differs quite significantly from other countries, which reflects a unique ethical and policy landscape.
In 2019, the Federal Joint Committee (G-BA), which plays a significant role in overseeing healthcare decisions and legislation, recommended that NIPT be reimbursed through public insurance. Following this recommendation, NIPT will be offered on a case-by-case basis, when a pregnant woman and her doctor together decide that the test is right for her. Communication from the G-BA emphasises that this model means that the NIPT cannot be considered part of a population prenatal screening program (Reihenuntersuchung). In addition, where other countries emphasise enhancing reproductive autonomy and informed choice as the purpose of prenatal screening, the German policy rather explicitly states that the purpose of publicly funding NIPT is to decrease the rates of invasive testing (and possible associated miscarriages). The G-BA recommendation was accompanied by heated debate. There have been criticisms from healthcare professionals that the model is effectively tantamount to first-tier screening. In public discourse, concerns relating to selective reproduction, eugenics and disability discrimination are prominent. Related to this is the focus on human dignity in German legislation concerning the foetus. Furthermore, reproductive autonomy is more often examined through the lens of the "right not to know" and the possible threat of "routinisation" of NIPT.
This ethical and policy landscape results from a distinctive cultural and historical context with a strong influence on healthcare decision-making. We discuss how the German policy approach, unique in Europe, reflects how the echoes of the past shape approaches to new biotechnologies.

(7) Title: A Review on Islamic Perspectives on Prenatal Diagnosis and Termination of Pregnancy

Authors: Noor Jaser, PhD candidate, KU Leuven

Abstract:
The introduction of the various medical technologies at the beginning of life, including prenatal diagnosis, have raised delicate ethical questions. The hardest among which is whether to continue or terminate the affected pregnancy. Decisions surrounding prenatal diagnosis are heavily value driven. In this context, religious beliefs often play a major role in the choices families make. Yet, the examination of ethical issues on the beginning of life regarding prenatal diagnosis concentrates mainly on secular and/or Christian ethics, whereas Islamic ethics are notably under-investigated. Additionally, research on the topic focuses mostly on experiences and attitudes of Muslim parents and their healthcare providers rather than on Islamic ethical stances, views, or perspectives. This paper aims to review and analyze the Islamic ethical perspectives on beginning of life issues regarding prenatal diagnosis and termination of pregnancy. It also aims to examine the methods and frameworks that are deployed to resolve contemporary issues pertaining to prenatal diagnosis and termination of pregnancy. Importantly, this paper aims to point out existing gaps in the literature and demonstrates the importance of understanding the Islamic perspectives on the beginning of life in antenatal care. In line with the interdisciplinary nature of the field of bioethics, this paper raises important issues at the intersection of medicine, religion, and healthcare, and aims to create a productive dialogue between them. This paper aspires to help establishing cultural/religious sensitivity in health care, especially in multi-cultural Europe, and raise awareness on the existence of world-views other than the dominant western view on bioethics, in the context of antenatal care.

(8) Title: Should non-invasive prenatal testing be used for fetal sex determination? An interview study exploring healthcare professionals' attitudes towards and experiences with early fetal sex determination in Belgium.

Authors: Zoë Claesen, PhD Candidate, KU Leuven - Centre for Biomedical Ethics and Law

Abstract:
Background: Non-invasive prenatal testing (NIPT) is typically performed early during pregnancy and aims to enhance reproductive autonomy by obtaining genetic information about the fetus. NIPT is currently primarily aimed at trisomy 21, 18, and 13. Other information, like fetal sex, is typically reported as a secondary or incidental finding. NIPT can determine fetal sex very accurately very early. However, whether fetal sex should be determined by NIPT is ethically contentious. In Belgium, NIPT is very accessible because it is offered to all prospective parents and women only co-pay €8,68. Furthermore, the test uptake is very high (91%) compared to other countries, and fetal sex is routinely reported.
Objective: To assess the attitudes towards and experiences with early sex determination with NIPT of healthcare professionals in Belgium.
Methodology: We conducted a semi-structured interview study using thematic analysis. We interviewed 32 healthcare professionals in Belgium, representing a broad range of specialties, such as geneticists, gynecologists, midwives, laboratory technicians, pediatricians, and genetic counsellors.
(Preliminary) results: Healthcare professionals are divided on the issue whether fetal sex should be determined by or reported after NIPT. Many healthcare professionals do not consider early fetal sex determination by NIPT as problematic and find that fetal sex is important information for most prospective parents. Most healthcare professionals find sex-selective abortion not acceptable. Some participants against sex-selective abortion, reasoned that fetal sex should not be reported because it is non-actionable information. Worries concerning sex-selective abortion and the sense that 'we should not want to choose the sex of our children' were the among main reasons cited against fetal sex determination by NIPT. Some healthcare professionals worried that fetal sex reporting might compromise informed decision-making about NIPT.
(Preliminary) Conclusion: Even though healthcare professionals in Belgium disagree why fetal sex should or should not be determined by NIPT, generally, healthcare professionals do not find it very problematic in the Belgian context. Rather than ceasing fetal sex reporting after NIPT, the primary proposed solution for problems that were raised was improved pre-test counseling both in terms of quality and availability.

(9) Title: Congenital infections and right to terminate pregnancy: a case of congenital cytomegalovirus infection

Authors: Matteo Gulino, Assistant Professor, Department of Clinical Sciences and Translational Medicine, University of Rome "Tor Vergata" and Gianluca Montanari Vergallo, Associate Professor, Department of Anatomical, Histological, Medico-Legal and Orthopaedic Sciences, University of Rome "La Sapienza"

Abstract:
Objective: Prenatal diagnosis of congenital malformations incompatible with life or associated with high morbidity may represent a reason for the late voluntary termination of pregnancy. Congenital cytomegalovirus infection may cause congenital malformations and development disorders.
This study analyses a recent decision delivered by the Italian Supreme Court concerning the right to late termination of pregnancy and doctor's informed consent duties in a case of congenital cytomegalovirus diagnosed

at the 22nd week of gestation. An overview of EU countries' legal systems is also provided.
Methods: A bibliography research using "PubMed" and "Scopus" databases have been performed to define symptomatology, diagnosis, treatment and prevention of congenital cytomegalovirus, even in comparison with other congenital infections. Legal sources are also examined.
Results: As in most countries, Italy permits woman's access to voluntary termination of pregnancy on request at least up to the first trimester. Beyond these limits, this practice is offered for stricter reasons, such as the risk to the woman's life or mental and physical health. Law no. 194/1978 provides that voluntary termination of pregnancy after the first 90 days can be carried out when serious "risk to woman's psychical and physical health" arises from detecting pathological processes, including those related to anomalies and malformations in the foetus. The ascertainment of these clinical conditions may lead to extending voluntary termination of pregnancy in controversial situations, depending on clinical requirements and gestational limits provided by the law.
The poor prognosis associated with CMV primary maternal infection diagnosed early and the low incidence of symptomatology led to question the ethical and medico-legal concerns regarding late voluntary termination of pregnancy.
According to the Court, the diagnosis of pathological processes that cause, with an appreciable degree of probability, significant anomalies or malformations in the foetus may permit access to voluntary termination of pregnancy where the woman's physical and mental health is at risk; this is irrespective of whether the anomaly or malformation has already occurred and has been instrumentally or clinically ascertained.
Conclusions: The option for late voluntary termination of pregnancy in case of congenital cytomegalovirus infection may constitute a controversial health policy issue.

(10) Title: To offer an expanded screening in routine antenatal care in France? Practical questions and ethical issues related to the evolution of the NIPT technique in genomics

Authors: Adeline Perrot - post-doctoral researcher - Ethox Centre (Oxford University)

Abstract:
Non-invasive prenatal testing (NIPT) is a rapidly developing technology that is constantly widening its scope in fetal medicine. Since January 2019, NIPT is reimbursed in France for trisomy 21 (often including testing for trisomy 13 and 18). In January 2020, the French laboratory Cerba started to offer expanded screening tests beyond the common trisomies (T21, T13 and T18). In November 2020, the professional society, Association of Cytogeneticists, published recommendations for the use of 'expanded NIPT' (including for a wider range of rare autosomal trisomies, duplications and deletions ≥ 7 Mb). This second version of NIPT is based on whole-genome sequencing and is now available in several hospitals, midwifery and gynaecology practices in France, as a reimbursed second-tier test. Despite the potential benefits of expanded screening, it also raises a number of ethical issues. As part of a wider comparative research project between England, France and Germany, we conducted a literature review and semi-structured interviews in France with women/couples (10), healthcare professionals (HCPs) and scientists (20) to investigate ethical questions and concerns associated with 'expanded NIPT'. Our interviews show that, besides criticising some of the technical limitations of the test (lower accuracy than for the three common trisomies), HCPs expressed concerns about: the expanded scope of the screening for 'less severe' conditions; the potential expansion of indications for termination of pregnancy; obtaining valid consent for 'expanded NIPT'; the lack of training by those prescribing this test on how to inform women (gynaecologists, midwives and GPs); and the lack of equitable access of this new version of the NIPT in different clinical settings and across France. In our presentation, we will critically engage with these issues raised by the HCPs in the light of our literature review and highlight how the concerns of the HCPs reflect the particular French context.

Parallel Session 3
Room: Sala Montoli
Chair: Maria Aluas

(11) Title: Neonatologists' ethical decision-making for (non)resuscitation of Extremely Preterm Infants: ethical challenges and strategies

Authors: Alice Cavolo, M.Sc., Centre for Biomedical Ethics and Law, KU Leuven, Leuven (BE); Authors: Alice Cavolo, MA, Bernadette Dierckx de Casterlé, RN, PhD, (KUL) Gunnar Naulaers, MD, PhD,(KUL) Chris Gastmans, PhD (KUL)

Abstract:
Uncertainty of outcomes makes it difficult to decide whether to resuscitate extremely preterm infants (EPIs). Ethical questions quickly arise: should we always prolong life as much as possible? Is palliative care better in some cases? However, these questions are merely theoretical. It is still unclear what are the main ethical challenges met by neonatologists while making resuscitation decisions for EPIs and what strategies they use to tackle these challenges. To understand that, we interviewed 20 neonatologists from 10 neonatal intensive care units all-over Belgium.
We found that neonatologists perceived three main ethical challenges in this decision-making. The biggest challenge were conflicts between the principles of respect for parents' autonomy and the infants' best interest. Conflicts occurred when interviewees believed that parents' request was against the EPI's best interest. Neonatologists struggled understanding whether overriding parents' autonomy was ethically appropriate and how to do so in a sensitive way. The second challenge were conflicts with the guidelines. Although all neonatologists agreed on the importance of having guidelines, they also admitted that sometimes they become a limitation. For example, in Belgium guidelines allow parents to choose non-resuscitation at 25 week, whereas some participants felt uncomfortable with accepting parents' non-resuscitation requests at this week. The last challenge was dealing with uncertainty. Given the high uncertainty on the outcomes, determining whether resuscitation was appropriate is difficult.
We found two main strategies to deal with these ethical challenges. The first is "setting limits". This consists of restricting parents' requests to varying degrees to promote the EPI's best interest. For example, if parents want resuscitation for an infant with bad prognosis, neonatologists would propose to attempt resuscitation without going so far as administering adrenaline. The second was "trial of treatment". This consists of resuscitation and admission to intensive care on the premise that if the prognosis worsen, treatment will be withdrawn. When these strategies worked, participants felt they managed to balance parents' autonomy and the child's best interest. However, when these strategies failed they often developed long lasting moral distress as they felt they actively harmed the child.

(12) Title: No wrong decisions in an all-wrong situation. A qualitative study on the lived experiences of families of children with diffuse intrinsic pontine glioma

Authors: De Clercq Eva (Dr); Streuli Jürg (Dr. med.)

Abstract:
Background: Diffuse intrinsic pontine glioma (DIPG) is a rare, but lethal pediatric brain tumor with a median survival of less than one year. Existing treatment may prolong life and control symptoms, but may cause toxicity and side-effects. In order to improve child- and family-centered care, we aimed to better understand the treatment decision-making experiences of parents as studies on this topic are currently lacking.
Procedure: The data for this manuscript came from 24 semi-structured interviews with parents whose children were diagnosed with DIPG in two children's hospitals in Switzerland and died between 2000 and 2016. Analysis of the dataset was done using reflexive thematic analysis.
Results: For most parents the decision for or against treatment was relatively straightforward given the fatality of the tumor and the absence of treatment protocols. Most of them had no regrets about their decision for or against treatment. The most distressing factor for them was observing their child's gradual loss of independence and informing them about the inescapability of death. To counter this powerlessness, many parents opted for complementary or alternative medicine in order to "do something". Many parents reported psychological problems in the aftermath of their child's death and coping strategies between mothers and fathers often differed. Palliative care seemed for most parents not a known resource.
Conclusion: The challenges of DIPG are unique (i.e. lethal from the start; short life expectancy, absence of long-term parent-clinician relationship) and explain why parental and shared decision-making is different in DIPG compared to other cancer diagnoses. Considering that treatment decisions shape parents' grief trajectory, clinicians should reassure parents by framing treatment decisions in terms of family's deeply held values and goals. Our findings suggest that oncology teams should start the conversation about palliative care from the time of diagnosis. For this purpose, palliative care

(13) Title: Physicians' perceptions on decision-making about withholding/withdrawing life-sustaining treatments in paediatric patients: A systematic review of qualitative evidence

Authors: Yajing Zhong, MSN, PhD candidate, Centre for Biomedical Ethics and Law, Faculty of Medicine, KU Leuven, Belgium. Alice Cavolo, MA, PhD candidate, Centre for Biomedical Ethics and Law, Faculty of Medicine, KU Leuven, Belgium. Veerle Labarque, MD, PhD, Professor, Centre for Molecular and Vascular Biology, Faculty of Medicine, KU Leuven/UZ Leuven, Belgium. Chris Gastmans, PhD, Professor, Centre for Biomedical Ethics and Law, Faculty of Medicine, KU Leuven, Belgium.

Abstract:
Background: With paediatric patients, deciding whether to withhold/withdraw life-sustaining treatments at the end of life is difficult and ethically sensitive. Little is understood about how and why physicians decide on withholding/withdrawing life-sustaining treatments in paediatric patients with life-threatening conditions. In this study, we aimed to synthesise results from the literature on physicians' perceptions about decision-making when dealing with withholding/withdrawing life-sustaining treatments in paediatric patients.
Methods: We conducted a systematic review of empirical qualitative studies. Five electronic databases (Pubmed, Cinahl®, Embase®, Scopus®, Web of Science™) were exhaustively searched in order to identify articles published in English from inception through March 17, 2021. Articles were included based on the predefined criteria: (1) empirical studies using qualitative design; (2) English language articles; (3) physicians; (4) withholding/withdrawing life-sustaining treatments; (5) perspectives. Analysis and synthesis were guided by the Qualitative Analysis Guide of Leuven. We read articles repeatedly, identified the themes, tabulated, compared and analysed the data descriptively.
Results: Thirty publications met our criteria and were included for analysis. Overall, we found that physicians agreed to involve parents, and to a lesser extent, children in the decision-making process about withholding/withdrawing life-sustaining treatments. Our analysis revealed that physicians divided their decision-making into three stages: (1) early preparation via advance care planning, (2) information giving and receiving, and (3) arriving at the final decision. Physicians considered advocating for the best interest of the child and of the parents as their major focus. We also identified moderating factors of decision-making, such as facilitators and barriers, specifically those related to physicians and parents that influenced physicians' decision-making.
Conclusions: By focusing on stakeholders, structure of the decision-making process, ethical values, and influencing factors, our analysis showed that physicians generally agreed to share the decision-making with parents and the child, especially for adolescents. Approaches for evaluating young children's capacity for making end-of-life decisions are still unclear and need to be explored further. Further research is required to better understand how to minimise the negative impact of barriers (e.g., difficult involvement of children, lack of paediatric palliative care expertise, conflict with parents) on the decision-making process.

(14) Title: Fostering ethical reflection on health data research through co-design: a pilot study

Authors: Joanna Sleigh, doctoral candidate, Health Ethics & Policy Lab, Dep. of Health Sciences and Technology, ETH Zurich. Dr. Julia Amann, doctoral candidate, Health Ethics & Policy Lab, Dep. of Health Sciences and Technology, ETH Zurich.

Abstract:
Ethical frameworks constitute essential tools for education, awareness, and guiding healthcare research and practice. However, critical challenges to their adoption include their voluntary nature as soft law instruments and their lack of tailoring to researchers' needs. The abstract and conceptual knowledge communicated also leaves users to seek more operationalised guidance in checklists. However, this approach does not support reflection on the meaning of principles nor their ethical implications, leading to a formulation-implementation gap in Bioethics that limits the impact of ethical frameworks.
To explore more participatory and reflective practices, we pilot-tested a co-design approach that engaged end-users in visualising ethical principles that build the foundation of many ethical frameworks. Our goal was to investigate if this process would foster engagement, understanding and comprehension of bioethics principles amongst participating health researchers. A secondary objective was co-designing visuals that could be made public and used alongside an existing ethical framework to motivate engagement and tangibility of abstract concepts.
Applying a co-design methodology and using the Swiss Personalized Health Network's ethical framework as a case study, we invited health researchers (intended audiences of the framework) to participate in various co-design process phases. In two online workshops, participants partook in: individual reflection, collaborative ideation, prototyping, sketching, discussion, and evaluating the workshops and final visualisations.
The study resulted in four visuals utilising colour, shape, metaphor, and illustration to aid memory and interpretation. Study results demonstrate that the co-design process can foster in-depth participant engagement and ethical deliberation. Participants evaluated their workshop experience as enjoyable and concluded that visuals could motivate and improve bioethics communication. Concurrently, observational data suggest that the visualisation process cultivated heightened awareness of ethical issues in healthcare research.

To our knowledge, this is the first study outlining how to apply a participatory and design-oriented approach to help bridge the formulation-implementation gap in bioethics. Our study highlights the feasibility and value of involving intended users in designing visuals to promote education and awareness of ethical issues within healthcare research. Further, the study demonstrates how to produce visual content within text documents while fostering stakeholder dialogue and exchange on ethical principles and guidelines.

(15) Title: The surgical ethics gap

Authors: Kari Milch Agledahl, MD, PhD, MPhil. Finnmark Hospital Trust, Norway.

Abstract:
Surgery is often perceived as a field of action more than one of reflection, and surgeons have traditionally shown little interest in formal ethical deliberation. Despite of this, surgery has evident moral impact: Operating on defenceless and thus extremely vulnerable patients, mutilating body parts, should make ethical reflection very present indeed. Still, many perceive surgical ethics as an oxymoron. Ethical issues have traditionally been far more prevalent in medical than in surgical literature.
This is gradually changing, as ethics of surgery has become a growing field of publication. Surgical ethics deals with challenges and dilemmas that are not correspondingly found in non-surgical medicine, and thus warrant specific ethical reflection. Concurrent surgery, palliative surgery, standards of excellence and surgical innovation are examples of new issues brought forward by a specific focus on surgical ethics. These contributions enrich both the field of surgery and a more clinical oriented medical ethics, and an ongoing systematic literature search on surgical ethics constitutes the base of this presentation.
Of special interest is that preliminary results indicate an apparent gap in the literature on ethics of surgery and the associated accounts of surgery. Orthopaedics, gastro surgery, cardiac surgery or neurosurgery are all seen as action-oriented disciplines, even depicted with corresponding surgical personalities. Surgical disciplines are defined by their invasive procedures performed in the operating room, on sedated or unconscious patients. This is, interestingly, not reflected in the literature on surgical ethics. A search on surgery and ethics in the Medline database gives about 14 000 results. Less than 1 % of these papers discuss issues that take place inside the operating room.
While a growing field of knowledge, the literature on surgical ethics only rarely discusses the specific surgical activities within operating rooms. The presentation will describe this ethics gap, as well as reflect on explanations for this gap – that may be inherent in the discipline of clinical ethics.

Parallel Session 4
Room: Sala Giunta
Chair: Esquerda Montse

(16) Title: Recasting wellbeing in the context of serious mental illness

Authors: Jona Simon Carlet, resident doctor & B.A. philosophy, Psychiatric University Hospital - University of Zürich

Abstract:
Beneficence is one of the four foundational principles of medical ethics. It is usually interpreted as the duty to promote and protect the patient's wellbeing. Compared to somatic medicine, the application of this principle is more challenging in the context of serious mental illnesses as these conditions have a broad impact on a person's emotional and cognitive competences, as well as on the psychosocial aspects of her life.
Furthermore, it is not clear what is meant by wellbeing. Yet, despite its centrality in caring for patients, the conceptional foundations of wellbeing have received little attention in the corpus of medical ethics, especially in reference to mental illness. Consequently, professionals in psychiatry often lack a theoretical foundation for treatment recommendations aimed at promoting the patient's wellbeing.
This presentation introduces an understanding of wellbeing for the context of serious mental illness. First, I analyze different philosophical theories of wellbeing and discuss the advantages of a hybrid approach that combines objective and subjective criteria of wellbeing. I introduce a hybrid approach that integrates elements of the recovery concept, emphasizing psychosocial aspects of wellbeing in the context of serious mental illness. Finally, I discuss the potential of the presented understanding of wellbeing by applying it to a case example.
In the future, this hybrid theory of wellbeing could be used as an ethical basis for the development and implementation of clinical tools to promote the wellbeing of patients with serious mental illness.

(17) Title: Ought those who offer Psychedelic Therapies have first-hand experience of Psychedelic Drugs?

Authors: Dr Nathan Emmerich (Presenting Author) and Mr Bryce Humphries. The Medical School, Australian National University.

Abstract:
Research into psychedelics has recently undergone a renaissance and there is now good reason to think that various psychedelics—including psilocybin, ayahuasca, ketamine and LSD—may have significant therapeutic potential when it comes to treating those who suffer from Post-Traumatic Stress Disorder, existential distress, and addiction. Similarly, MDMA may soon play a role in couples therapy. Whilst the use of psychoactive drugs, such as Diazepam or Ritalin, is well established, psychedelics arguably represent a therapeutic step change. As experiential therapies their value does not lie in altering or rebalancing the brain's neurochemistry, but in inducing a subjective experience related to the patient's sense of self.
Some have suggested that there may be epistemic benefits for therapists to have first-hand experience of psychedelics. Just as monochrome Mary's knowledge increases when she first subjectively experiences colour, the idea is that the psychedelic experience might have similar epistemic significance. Whilst emerging evidence and traditional indigenous wisdom suggests that counsellors or guides can facilitate the proper integration of insights derived from psychedelic experiences, it is not clear whether first-hand knowledge of such experiences should be considered therapeutically valuable. Certainly no one supposes that professionals should have personal experience of other commonly used psychoactive compounds. Nevertheless, many would advance the view that experience of illness does contribute to an individual's therapeutic abilities. Similarly, some trainees are commonly required to experience the therapy they wish to provide and counsellors commonly undergo reasonably extensive counselling.
The idea is that experiencing what it is like to be emotionally vulnerable with a counsellor provides knowledge that cannot be generated by other means. Given the experience's psychedelics induce, comparable epistemic benefits may be on offer. However, whilst some of those who train to provide psychedelics therapeutically may be open to undergoing a psychedelic experience, it does not seem legitimate to require trainees to do so. This paper will therefore advance the view that whilst trainees should not be required to have a psychedelic experience the potential for epistemic benefit means that it is legitimate to allow those who wish to experience psychedelics as part of their training to do so.

(18) Title: How to deal with the duty of confidentiality in family involvement: Ethical challenges, barriers and possible solutions in the treatment of patients with psychotic disorders

Authors: Kristiane M. Hansson (first author): PhD research scolar, Centre for Medical Ethics, Institute of Health and Society, Faculty of Medicine, University of Oslo Maria Romøren: post.doc, Centre for Medical Ethics Lars Hestmark: PhD research scolar, Centre for Medical Ethics Kristin Sverdvik Heiervang: Associate professor, University of South-Eastern Norway Bente Weimand: Associate professor, University of South-Eastern Norway Reidar Pedersen: professor, Centre for Medical Ethics

Abstract:
Background: The uptake of family involvement in health care services for patients with psychotic disorders is poor, despite a clear evidence base, socio-economic and moral justifications, and guideline recommendations. To respond to this knowledge-practice gap, we conducted the cluster randomised controlled trial: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centres (IFIP). Among numerous barriers hampering the involvement of family members in treatment and decision-making processes, confidentiality issues constitute a major barrier. Nested in the IFIP trial, this sub-study aimed to explore what ethical challenges and barriers mental health professionals experience related to the duty of confidentiality in family involvement during the treatment of persons with psychotic disorders. We also explored what measures can improve the handling of such challenges.
Methods: We performed 21 semi-structured focus group interviews, including 75 participants in total. Implementation team members were interviewed at the initial and middle phases of the intervention period, while ordinary clinicians were interviewed in the late phase. A purposive sampling approach was used to recruit participants with various engagement in the implementation process. Data were analysed using manifest content analysis.
Preliminary results: We identified fourteen subthemes and four overarching themes that reflected the participants' experiences with confidentiality issues in family involvement. Two themes highlight barriers and ethical challenges: 1) Dealing with patient refusal 2) Lack of competence and legislation triggering moral distress. Two themes highlight measures to facilitate better handling of the duty of confidentiality: 1) Training in family involvement and confidentiality, followed by practice 2) Standardisation and routines.
Preliminary conclusions: During implementation, several participants underwent a vital change in terms of how they understood and enacted the duty of confidentiality. Before implementation, when lacking competence and experience in family involvement, maintaining patient autonomy and confidentiality was at the core of participants' professional practice, they experienced uncertainty in case of patient refusal and were faced by conflicting needs. During implementation, confidentiality issues was reframed, there was a changed weighting of principles and considerations, and core barriers dissolved.
We plan to submit an article on this issue during spring 2022.

(19) Title: Alternatives for Clinical Ethics Consultation in Psychiatry in Japan

Authors: Hiroyuki Sato, The University of Tokyo

Abstract:
The number of clinical ethics consultation has been increasing in recent years. In a survey of hospitals accredited by the Japan Council for Quality Health Care, 80 % of the hospitals have their own hospital ethics committee, and about 60% of the hospitals provide clinical ethics consultation.
In psychiatry, clinical ethics consultation is related to a wide range of fields such as compulsory hospitalization, dementia, living donors for transplantation, assisted reproductive technology, genetic counselling and palliative care. Cross-departmental collaboration is often required. Unlike other departments, psychiatry requires treatment that is sometimes against patient's wishes and hence there are some cases where a hospital advisory lawyer or the medical safety management department needs to be involved. In Japan, the number of psychiatric beds is 330,000, which is the largest in the world in terms of population ratio, and psychiatrists easily encounter various ethical dilemmas in their daily clinical practice. However, the number of clinical ethics consultation in psychiatry is still few. One of the reasons is that hospitals provide other supports, such as psychiatric liaison teams, palliative care teams, and dementia care teams. In addition, doctors often make decisions under the initiative of doctors. Also, designated physicians of mental health judge compulsory hospitalization, and then the physicians consider more legal matters than ethical ones.
In this study, I aim to discuss the strengths and weaknesses of clinical ethics consultation and other methods, focusing on dialogue in psychiatric clinical practice, taking into account the situation in Japan.
Finally, I conclude that medical institutions in Japan should change the way of clinical ethics support to patients depending on what resources they have and what services they can offer.

(20) Title: Cosmetic Neurology and Brain Enhancement: a neuro-ethical analysis

Authors: Marta Vassallo, PhD Candidate, Department of Biotechnology and Science of Life, Center for Clinical Ethics, Insubria University

Abstract:
From the moment we became increasingly aware of our capability of treating diseases and lessen their symptoms, we found ourselves able to manipulate health. The term cosmetic neurology refers to the use of neurologic interventions and psychotropic drugs to enhance our brain's performance, resilience to stress and trauma and simply to become better, even if we are healthy individuals. The investigation of these practices and their implications is utterly important, especially if we take into account various perspectives such as cognition, mood and feelings, but also considering the ethical issues of Safety, Authenticity, Justice and Society.
However, there is significant evidence guiding us towards the idea that, even though cosmetic neurology can be considered problematic, there can be, sooner than later, a concrete and plausible alternative to it, represented by non-invasive and not related to drugs brain enhancement techniques. Unfortunately, concerning the ethical investigation of these techniques, little research has been carried on.
In this paper my aim is to ethically analyse both invasive and non-invasive cosmetic neurology techniques, claiming that the latter are far less problematic when compared with the use of psychotropic drugs. Therefore, I argue that the ethical use of non-invasive brain enhancement would provide a better alternative and an important solution to drug-use in cosmetic neurology. More specifically, I maintain that a) these practices are exempt from causing side effects related to chronic drug assumption, and that b) they do not seem to alter our self-perception or the perception we have of the external world. Furthermore, in order to justify the use of non-invasive brain enhancement, I focus not only on the risks of these practices but also on their potential advantages provided both to the individual and to society. Given these premises, I conclude that we can still try to improve our cognition without creating major or unsolvable ethical issues while doing it.

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Friday, September 16th, 2022
Plenary Session 2: The dialogue in clinical practice

Chair: Federico Nicoli - Key lecture: Gerald Neitzke (Hannover Medical School, ECEN Network Steering Committee) Discussants: Massimo Cardillo (Italian National Transplant Center, National Institute of Health, Rome) Veronique Fournier and Nicolas Foureur (Centre d'éthique Clinique de l'hopital Cochin, Paris)



Dr. med. **Gerald Neitzke** is a clinical ethicist from Hannover/Germany. He works at Hannover Medical School (MHH), at the Institute for Ethics, History and Philosophy of Medicine, which he headed as interim director from 2013 to 2020. He is chairing the Clinical Ethics Committee at the University Hospital of MHH since 2000.

After finishing his studies in medicine and philosophy at Christian-Albrechts-Universität Kiel in 1993, he worked as a physician for two years in the field of internal medicine at St. Georg Hospital in Hamburg. He then moved to Hannover Medical School where he established medical ethics as a novel scientific specialty. He was awarded the Wilhelm-Hirte-Preis for excellence in teaching in 1999. His research topics cover ethics consultation and ethics committees, ethics at the end of life, and didactics of medical ethics. He is a certified trainer for ethics consultation (AEM). He is a member of the Steering Committee of European Clinical Ethics Network (ECEN) since 2015, and a member of the executive board of the German Academy for Ethics in Medicine (AEM) since 2012. He is also a longstanding member of the ethics section of DIVI (German Interdisciplinary Association of Intensive Care).

Abstract:

Communication is a tool we use to share knowledge and meaning. Ethics is the endeavour to strive for understanding in moral issues. Therefore, ethics – both in everyday clinical encounter and in the specific case of ethics consultation – is dependent on successful communication. Clinical ethics can be understood as the process of settling and clarifying moral issues in the hospital. Physicians, nurses, or ethicists search for common ground and understanding on the way towards a morally "good" patient care.

In the presentation, we will analyse in what way moral considerations, convictions, and attitudes are connected to central medical topics such as therapeutic goals, treatment options, medical indications, prognoses, risk-benefit-assessments, and quality of life. None of these topics are objective or value-neutral. They are deeply rooted in our ideas of well-being, of good care, and of a good life and death. Health care professionals and clinical ethicists have to be careful, how to discuss the value-laden aspects of these fundamental medical topics. Without an explicit moral discourse about the meaning and appropriateness of medical options and alternatives, a profound misunderstanding and inadequate clinical decisions will result.

For this reason, health care professionals need to be good communicators and should be aware of the tools to facilitate moral discourse. Ethics is not only about *what* we think or consider, but also about *how* we express it. Clinical ethics will be effective, if it contributes to support mutual understanding and decision-making in the hospital.



Dr**. Massimo Cardillo** has been officially appointed by the Italian Minister of Health as Director General of the Italian National Transplant Centre from March 11th 2019 for five years. Dr Cardillo graduated in Medicine at Milan University, he got a specialty as haematologist and he has been active in the organ donation and transplant field since 1992, being involved in management and coordination of Nord Italia Transplant, the first interregional organization that was set up in Italy.

Dr Cardillo is author of 84 scientific article on national and international journals and responsible of 11 scientific projects.

Abstract:

As of today, organ, tissue and cell transplantation is the most efficient therapy, and sometimes the only possible one, for many patients. Donation, procurement, and transplantation activities are characterized by profound ethical issues at all stages of the process. Donation after death is a choice which can be made explicitly in life, expressing a deep need for self-determination, or it can be left to family members after death which implies a more complex communication work for professionals operating in ICUs. Living donation is a free, voluntary, and gratuitous act which can be exerted to help a family member or a loved-one but also a stranger. In the last case, the system that shall be planned out should avoid any possible risk of commercialization while simultaneously providing forms of recognition that might inspire people to donate. Worldwide, the great imbalance between the number of patients who would benefit from transplantation and the organs available, is at the core of the complex issues arising from defining the criteria for organ allocation, which must comply with the principles of transparency, best use of a scarce resource and balance between equal access and benefit of treatment. Moreover, today, substances of human origin are increasingly being employed in the manufacturing of advanced therapies which bring them closer to the world of pharmaceuticals, making industry's involvement crucial. Therefore, it is essential to allow the development of new activities while maintaining the solid principles of donor protection and non-marketing of products. Also, the issue of accessing transplant in those parts of the world where there is not a universal health system is a pivotal one since transplant is an expensive therapy which can only be implemented by virtue of a free act of donation. Bringing together these two apparently conflicting aspects, is one of the main challenges that the future holds. Finally, there are two new frontiers: the possibility of modifying the DNA of some animals to make their organs and tissues more similar to those of humans and the development of bioengineering technologies. Both open to brand-new scenarios which make it possible to imagine xenotransplant and the use of artificial organs as a potential solution to the dramatic problem of lack of human organs.





Véronique Fournier is the founder of the first Clinical Ethics Center offering ethics consults on the clinical ground in France. She created it in 2002 in Assistance Publique-Hôpitaux de Paris and directed it from 2002 to 2020. Her main background is in medicine. She practiced for all her carrier as a cardiologist and a specialist in Public Health. In 2001, she was sent in the US by the French government to investigate the field of clinical ethics and test the opportunity of creating a clinical ethics service support in Paris, as a tool to promote patients' rights and a better dialogue between patients and doctors. Along the years she practiced clinical ethics, one of her main fields of interest and research has been about end-of-life issues. Probably due to this, the Minister of health asked her, in 2016, to become the first president of the newly created French "National Center for Palliative care and End of life", what she remained up to June 2020. She is now retired but still very much involved and socially active in the ethical questions surrounding the ageing, another of the important topic she learned to face and think about, during the years she practiced clinical ethics. Véronique Fournier is also one of the foundator of the ECEN (European Clinical Ethics Network) and the co-author of a Manuel of Clinical Ethics, published in 2021 in order to help the many clinical ethics support services that recently emerged in hospitals, in the wake of the Covid pandemics.



Nicolas Foureur is a physician, a dermatologist by training, who specializes in sexual health. He has also worked in geriatric care, with a focus on and wounds in the elderly.

He joined the Clinical ethics center (AP-HP – Paris) multidisciplinary group in 2003 and has worked as a clinical ethics consultant since 2006. He now directs the Center, after its founder, Véronique Fournier retired. His interests in clinical ethics include aging (medicalization, institutionalization, dependency, empowerment), psychiatry (autonomy, access to health care), sexual health (HIV prevention) and gender issues (intersexes, young transgender). He also works on the methodology of the clinical ethics consultation, and he is the coordinator of a national network devoted to promoting, and reflecting about, consultation services. He is also a member of the European Clinical Ethics Network, and he is active in promoting international exchanges about the practice of clinical ethics consultation, as well as its underlying assumptions. He is particularly focused on ways clinical ethics consultation will help "patients' voice" emerge and be respected. He is in charge of training in clinical ethics in order to promote pluridisciplinary work and to offer health care professionals the opportunity to get acquainted with clinical ethics basics.

Abstract:

Our Clinical Ethics Center was implemented in 2002, in application of the first French law on patients' rights. Its main goal was to help resolving ethics case-by-case conflicts at the bedside, when they block a medical decision to be made. In the beginnings, the presupposition that patients were as much legitimate as health care professionals to express an ethics position was not so much welcome in the French context, neither the involvement of non-caregivers in the ethics consult process. But progressively, the Center became recognized in its principle and methods and adopted by patients/proxies as much as by health care teams. Today, it serves as a model for the hospitals that want to have a CESS, which are numerous since the Covid pandemics. Moreover, health care professionals become demanding to be trained in clinical ethics. This good news does not prevent questions about the dialogue between clinical ethics and bioethics. If respect for patient autonomy became a reality in the field, one wonders to what extent it is well thought out and discussed to address newly emerging questions. For example, what to respond to worried parents calling when they face a gender transition request from their teenager? Should the respect for autonomy, i.e. auto-determination prevail in such cases? Or should other ethical arguments carry more weight than they seem to have today in the decision? In addition, social and economic issues might increasingly affect, in the near future, the health care field and modify the context in which case-by-case decisions would have to be taken. For example, if the number of caregivers become shorter and shorter in hospitals, will it be possible to continue ensuring good ethical care? To what extent such changes will be/should be included in our clinical ethics matrix of reasoning?

V. Fournier, N. Foureur. Aide-mémoire Éthique Clinique, Dunod, 2021, Paris

Abstract Book

Parallel Session 1
Room: 2TM
Chair: Richard Huxtable

(21) Title: Our Future Healthcare: Towards more Equal and Sustainable Medicine and Public Health

Authors: Lucia Galvagni, PhD, MA - Researcher, Bruno Kessler Foundation, Trento; Monica Consolandi, FBK PhD Program, Bruno Kessler Foundation, Trento

Abstract:
As a healthcare emergency, Covid-19 forced to restructure and rethink healthcare and its organization and has modified our way to look at healthcare needs and priorities. Considering changes realized and the ones at stake in healthcare, the presentation will illustrate a research conducted with healthcare professionals in Italy, to identify needs and priorities in medicine as they are perceived by clinicians, with the goal to define and understand possible future healthcare scenarios.
Main issues to reflect on have been priorities in healthcare, relevance of communication and new technologies, any possible role for spirituality in healthcare and the evaluation of different healthcare models. These elements seem to be relevant to guarantee more equal and sustainable medicine and public health.
The presentation will analyze and discuss the results of this research, underscoring how experiences and competencies of healthcare professionals - working in different fields and contexts - can contribute to define our future healthcare.

(22) Title: Health and future of humans: the need for a global right to protect the environment

Authors: Policino F., MD, PhD, Marisei M., MD, Dei Medici S., MD, Casella C., PhD, Capasso E. MD, PhD, Niola M. Full Professor- Dep. of Advanced Biomedical Science- Legal Medicine- University Federico II- Naples

Abstract:
Every environment on Earth e is characterized by the presence of existences (animate or living-biological; inanimate / material-non-biological). The Earth is characterized by being made up of material or abiotic existences (environmental matrices: atmosphere, water, soil) and living or biotic (people, monere, plants, animals, fungi and protists).
The human species - by virtue of the intellectual functions that have made it capable, more than other biotic existences, to manipulate every environment by artificially influencing it the existence of the different from itself, the inter-relationships between the different existences, the natural flows of matter and energy always present between different environments - continues to be (in life and in health), however, often to the detriment of other existences.
In fact, human manipulative activity has created a series of artificial dangers (additional to natural ones) of such single importance (referring to nuclear energy) as to be predictably capable of causing the disappearance of existences (non-living and living beings, including the human) as well as of the Earth itself as it has come to us today.
Today more than ever Humanity must strongly feel the ethical duty to commit itself, as far as it can or through the Law, to offer protection its inhabitants whether animate or material, exists externally.
In Italy the Constitutional Law of February 11, 2022, n. 1 containing "Amendments to articles 9 and 41 of the Constitution regarding environmental protection" introduces two main changes to two articles of Constitution, without giving any definition of the environment itself.
Neither in "EU Charter of Fundamental Rights" fully into force with the Treaty of Lisbon on 1 December 2009 has a correct definition of environment been given.
The authors therefore propose a definition of environment in relation to life.

(23) Title: The Bioethical Implications of Human and Non-Human Biosurveillance: Towards an Integrated One Health and Global Justice Framework

Authors: Emma Nance, Wellcome Trust-funded 1st Year PhD candidate: University of Edinburgh, Usher Institute, Centre for Biomedicine, Self, and Society; Supervisor Dr. Sarah Chan: University of Edinburgh Usher Institute, Centre for Biomedicine, Self, and Society

Abstract:
As demonstrated by the COVID-19 pandemic, increased identification and communication of emerging infectious diseases, especially zoonotic crossovers, are crucial to controlling disease outbreaks. However, there remains a marked lack of integration between human, animal, plant, and environmental health sectors. While the One Health paradigm aims to foster greater interdisciplinarity, more research into the ethical implications of integration is urgently needed. My research investigates the bioethical aspects of both human and non-human biosurveillance activities, ultimately aiming to integrate both strands under a One Health and global justice framework.
First, I am investigating how recognising and attending to non-human health should improve overall global health without exacerbating structural injustice. Next, I am exploring the ethical implications of human biosurveillance activities, such as contact tracing and wearables, specifically considering the effects on marginalised communities. Third, I will analyse the role of global justice and what, if any, ethical principles should guide emerging and future biosurveillance actions. Finally, I aim to integrate the ethical aspects of both human and non-human biosurveillance strands under a One Health and global justice framework. Thus, my research aims to provide greater insights into the shared ethical responsibilities of biosurveillance actions, moving towards an integrated One Health and global justice framework.

(24) Title: Do new medical technologies have any value in a heated world?

Authors: Dr Richard Nicholson. Retired editor, Bulletin of Medical Ethics. Founder, EACME

Abstract:
Global heating presents medicine with a paradox: the more effort medicine puts into saving individual humans, the more likely it is that the human race will not survive.
The climate and environmental crises are caused by having too many humans using too many natural resources. Healthcare and its infrastructure are major contributors to excessive use of resources - think of the enormous use of disposables, particularly plastic, that has developed since I was a medical student 50 years ago. Healthcare is also a

positive feedback mechanism to make the situation worse. Its primary purpose is to help people to live longer, more active lives, ie to have more humans alive and using more natural resources for longer. That, for instance, produces more opportunities to misuse antibiotics, producing antibiotic-resistant infections needing even more healthcare. It also drives humans to live in unsettled territory, close to a variety of fauna, leading to new infections such as Covid - which has produced a massive increase in the use of healthcare.
If the human race is to survive, most people in developed countries will have to live much simpler lives, with much less healthcare. Since survival also depends on having a much more equitable global society, less developed nations must be allowed to develop healthcare to a good basic level. There is, therefore, the need for a complete rethink about the level of healthcare that is sustainable in any country, and on how in practice to ration or otherwise limit healthcare in rich countries. The test for whether or not to permit a particular form of healthcare might well be to ask 'Does it help the human race to survive?' My view is that most recent technological advances cannot help survival within the limits of resource use needed for sustainability. Nor can many older technologies such as organ transplantation.
It is high time that bioethicists looked up from the minutiae with which they concern themselves, saw the imminent danger of human extinction and started a major debate on the future, if any, of modern healthcare.

(25) Title: Medical and environmental ethics: conflict or synergie?

Authors: Kasper Raus (professor - Postdoc UZGent & UGent) - Eric Mortier (professor Ugent & UZ Gent) - Kristof Eeckloo (professor UGent & UZ Gent)

Abstract:
It is said that the hospital of the future will be smart, but the question is whether it will also be green? The health care sector is a particularly large one and, as is well known, a very resource intensive one. This concerns their use of natural resources (e.g. clean water, helium, oxygen, etc.), their use of hazardous chemicals, and their large carbon footprint. A final issue of the production of a large amount of waste, partly due to the widespread use of disposable medical equipment (e.g. disposable syringes, needles, and latex, rubber or vinyl gloves. Besides this solid waste there is also a large amount of hazardous waste that is often incinerated and is particularly polluting.
In view of the climate change challenges before us, it is clear that we will need to work towards sustainable health care and green hospitals. However, it has been suggested that conflict might arise between clinical/medical ethics and environmental ethics. Whereas clinical ethics might prioritize the individual patient, environmental ethics might prioritize the ecosystem. For example, using reusable syringes and sterilizing them might reduce the amount of solid waste and improve sustainability, but it is known that prions can resist standard sterilization. This means reducing the solid waste in this way may come at a small (but potentially very severe) risk for the individual patient.
Considering the challenges, we need to find a way to bridge the potential gap between the clinical ethics way of thinking and the environmental ethics one. Starting from a university hospital we will examine several challenges and consider several ways in which improving sustainability of hospitals can go hand in hand with the clinical ethics thinking that is particular to the health care setting. Our argument will also be based on existing literature on this topic. We believe it is necessary to consider a medical ecological philosophy (MEP) that stresses the healthy patient in a healthy environment.

Parallel Session 2
Room: 3TM
Chair: Stef Groenewoud

(26) Title: The is-ought gap reconsidered - improving day-to-day ethical deliberations on an epistemological level

Authors: Cand. Dr. med. Thu Hang LE and Prof. Dr. Rouven Porz, Medical Ethics Unit, University Hospital of Bern, Medical Faculty, Bern, Switzerland

Abstract:
The conduct of ethical case deliberations in the context of clinical ethical support always involves the ambivalence of descriptive facts and normative conclusions (is-ought-gap). Most of the time, philosophically untrained health professionals are not even aware of this hurdle.
In our recent study, we examined the ethical case discussion protocols of the last 10 years of the University Clinic for Gynaecology (in the University Hospital of Berne) with the aim of determining which facts (and/or normative foundations) were decisive in the respective case discussion situations in order to be able to make a respective treatment decision.
In this interpretative study, it emerged that the supposed reference to 'evidence-based medicine' represents the greatest certainty for health professionals in decision-making, but that relevant concepts of 'disability', or alternative 'ethical theories' such as Care Ethics, are almost completely absent from the decision-making. Based on these results, we would like to derive new implications for the facilitation and organization of ethical case discussions in the clinical context. In our talk we would like to put these implications up for discussion.

(27) Title: A plea for patient (virtue) ethics in the clinic

Authors: Jos Kole, assistant professor Ethics of Healthcare, Radboud university medical center, Nijmegen, The Netherlands

Abstract:
Patient-ethics (concerning the moral responsibilities of patients towards others and themselves) and especially patient virtue ethics are still largely neglected topics in clinical ethics – if there is a gap to be noticed in clinical practice, it is this one!
The positive claim defended in this paper is that more clinical-ethical attention should be paid to patient ethics and patient virtues, to enable all members of the moral clinical community to flourish, each in his/her own way, in response to one's own circumstances and context, to the extent possible given these circumstances.
To defend this claim I first (re)introduce patient ethics and, more specifically, patient virtue ethics, in dialogue with the relative small body of literature on both topics (see e.g. Miles, 2019). Then I discuss arguments why neglect of this type(s) of ethics is undesirable and more attention should be paid to this approach.
An important line of argument will be that a patient (virtue) ethical approach corrects the current onesided focus in bio- and clinical ethics on professionals as 'moral agents' and patients as 'moral patients' (objects of moral concern). It stresses the consequences of the idea that clinics are moral communities in which all members, both patients and professionals, can and should be considered as both moral subject and moral patient.
The paper ends with a research agenda that shows the interesting and inspiring questions that still have to be answered in further patient (virtue) ethical research in a clinical context.

Statement: The author wants to be transparant about the 'history' of this abstract. It was submitted and accepted for the ICCEC-Stellenbosch conference 2021 but unfortunately due to technical problems during this hybrid conference it was never actually presented and discussed.

(28) Title: Nothing about the patient without the patient? Involvement of patients and their relatives in clinical ethics consultation

Authors: Jan Schürmann, PhD candidate, Clinical Ethics Unit, University Hospital Basel (USB) and University Psychiatric Clinics Basel (UPK), Institute for Biomedical Ethics and History of Medicine (IBME), University of Zurich, Zurich, Switzerland; PD Dr. Dr. Manuel Trachsel, Clinical Ethics Unit, University Hospital Basel (USB) and University Psychiatric Clinics Basel (UPK), Institute for Biomedical Ethics and History of Medicine (IBME), University of Zurich, Zurich, Switzerland; Prof. Dr. Dr. Ralf Jox, Institute of Humanities in Medicine, Lausanne University Hospital and University of Lausanne, Lausanne, Switzerland

Abstract:
Most approaches to clinical ethics consultation (CEC) aim to fully involve patients and relatives in its process. Empirical studies, however, show that patients and relatives rarely request or participate in CEC. This discrepancy has been attributed to a lack of awareness, misunderstandings, or power asymmetries. Yet, it may also be due to the lack of a normative framework about patient and relative involvement in CEC. The aim of this work is to develop such a framework, based on the following research questions: 1) Which forms of patient or relative involvement in CEC are reported in the literature? 2) How often are patient and relatives involved in CEC? 3) Which arguments are advanced for and against patient and relative involvement in CEC? A scoping literature review of different forms, frequencies, and arguments on patient and relative involvement in CEC was performed, followed by a conceptual and normative analysis that was used to build a framework about patient and relative involvement in CEC. Ten different forms of patient and relative involvement in CEC could be distinguished: general awareness, specific awareness, positive access, negative access, participation, privacy, engagement, documentation, representation, and feedback. Arguments in favor of involvement include ethical ones (e.g., respect for autonomy, compliance) and political ones (e.g., subsidiarity, democratic participation), while arguments against involvement are mainly practical ones. A framework is presented that locates these forms in a process model of CEC. Recommendations are provided that consider the various contexts and activities of CEC. The inclusion of patients and relatives is an often formulated but rarely realized goal in CEC. The presented framework can be used to better implement appropriate involvement and this advance the quality of dialogue in clinical ethics.

(29) Title: Young people, the alcohol industry, and the concept of personal responsibility

Authors: Calum Smith, PhD student, University of Oxford

Abstract:
Introduction: Young people exist in a policy environment wherein the imperative to exercise 'personal responsibility' may be in conflict with social media-based techniques used by unhealthy commodity industries that encourage behaviours like drinking and gambling. Increasingly, these techniques involve collection of personal data, and big-data based recommender algorithms are able to recognise and align product advertising with young people's interests, increasing the efficacy of advertising. For example, targeted advertising may be directed at young people to show that alcohol consumption is compatible with, and even a good way to demonstrate participation in, certain activities (e.g. fitness or social justice activism). This raises philosophical and ethical questions around how we define 'personal responsibility' both on a personal level and within policy.
Methods: In this paper, I aim to lay out how the commercial determinants of health interact with and problematise the notion of 'personal responsibility'. I provide specific case studies from both industry and government that encourage that individuals exercise 'personal responsibility'. I present this alongside philosophical conceptions of personal responsibility, and use this framework to analyse whether big data-based recommender algorithms on social media undermine capacity to freely exercise personal responsibility.
Outcomes and conclusion: I argue that conditions for exercising 'personal responsibility' may not be truly met in a philosophical sense in circumstances where unhealthy commodity industries use big data based recommender algorithms to encourage consumption of e.g. alcohol and gambling. As bioethics looks towards the future, it is important to investigate ethical issues surrounding the relationship between social media, big data use, and promotion of unhealthy commodities. These relatively new and emerging technologies deserve bioethical attention due to their potential health impacts. Combining research into the mechanisms through which big data based algorithms may influence health choices with philosophical analysis of the concept of personal responsibility provides a promising example of how bioethics is able to meaningfully bridge the gap between theory and practice.

(30) Title: The Ethics of Stakeholder Engagement; What happens when Clinical Ethics Support and Responsible Innovation meet?

Authors: Dr. Mira Vegter, Dr. Margeet stolper, Prof. Dr. Bert Molewijk. VU Medical Centre

Abstract:
Stakeholder engagement is a central feature of Responsible Innovation (RI) and common to Clinical Ethics Support (CES). Moral Case Deliberation (MCD) is a well-established practice in CES and just like many RI trajectories it has in common that joint deliberation based on a specific case or context, is meant to determine 'what is the right thing to do'. Nevertheless do both fields tend to look for reconciliation of conflicting perspectives and therefor risk to undermine important stances for the sake of consensus. Obviously consensus building is an important feature and perhaps morally speaking fundamental to establishing common ground for clinical ethics. However in this paper we investigate whether and what moral case deliberation can learn from 'the ethics of stakeholder engagement' – a Levinian take on RI procedures that appreciates irreconcilable difference. How to deal with difference? While MCD might strengthen by investigating the ideal of 'otherness'; MCD might also provide a robust practice for RI to deal with the problem of difference.

Parallel Session 2
Room: 4TM
Chair: Paolo Severgnini

(31) Title: Reshaping reproductive solidarity by deconstructing the family - bioethical tools and social regulation in dialogue.

Authors: Emma Capulli, PhD student, University of Insubria

Abstract:
In contemporary neoliberal societies, the strength of solidarity as a fundamental principle in health care is increasingly weak. In recent

years economic logic has pervaded the healthcare system, a process that is particularly evident in the field of assisted reproduction technologies (ARTs), characterized by the spread of reproductive outsourcing. This form of outsourcing is especially evident in the so-called third-party reproduction that is based, among other things, on the invisibilisation of the external subjects who take part in it. This is due to the globalization of ARTs circuits, but also to a biological and heteronormative approach to reproduction, which at both cultural and juridical levels affirms a specific parental and family model. Starting from that, I will highlight how the concept of reproductive solidarity can be reshaped by operating internally and externally to the bioethical field. Internally, through the implementation of sharing models of reproduction such as the mirror donation model, which provides an exchange between couples by eliminating anonymous donation. Externally, by challenging our social and legal construction on how families are made. This contributes to a moral framework where external participants of third-party reproduction are not intended only as parts of an accumulation process but are reconsidered in a more complex scenario. The text aims to investigate the possibility of reshaping the concept of reproductive solidarity, making monetary incentives less important, through strategies capable of strengthening and expanding social cohesiveness. The result shows one of the possible declinations of the existent link between concepts operating in bioethics and socio-political tools.

(32) Title: Confidentiality in moral case deliberation: questions on preconditions for open dialogue

Authors: Wieke Ligtenberg (junior researcher), Margreet Stolper, Bert Molewijk (Amsterdam UMC)

Abstract:
Ethics support staff often help others to deal with moral challenges. However, they themselves can also experience moral challenges when practicing clinical ethics support (CES). Facilitators of Moral Case Deliberation (MCD) for example may experience moral challenges when it comes to maintaining or breaching confidentiality. In this presentation we will present our project on moral challenges related to confidentiality in moral case deliberation (MCD). Facilitators might find themselves compelled to intervene or act upon things they hear or see whilst facilitating a MCD. For example, a MCD facilitator finds out that a participant does something illegal. Or, what to do if a MCD facilitator is asked to inform the Inspectorate about details of a MCD? When is a facilitator allowed or obligated to breach confidentiality and share information with others? How to make such a decision? And, if one decides after careful deliberation that it is perhaps allowed to breach confidentiality, how then should he/she do this in a morally sound way? Currently there is no normative guidance on how to act upon these questions.
In this presentation we will discuss MCD facilitators' experienced moral questions on confidentiality, considerations on appropriate courses of action when decided to breach confidentiality, and reported needs for ethics support. We will show results from our empirical research amongst facilitators MCD and present data collected through interviews, MCD's on moral challenges related to confidentiality, focus groups, expert interviews, and thinking aloud interviews. In this presentation, a dialogue will be started about confidentiality in ethics support and the ethics support needs of facilitators MCD.

(33) Title: Empowerment of Moral Craftsmanship; results of series of Moral Case Deliberations with Dutch prison staff

Authors: Anne I. Schaap MA, dr. M.M.Stolper, prof. dr. B.C. Molewijk; Department of Ethics, Law and Humanities, Amsterdam University Medical Centre

Abstract:
Moral Case Deliberation (MCD) aims to promote professionals' joint moral reflection about complex situations from practice. In 2017 we started a research project – together with the Dutch Custodial Institutions Agency (DCIA) – where we supported the implementation of MCD-sessions for Dutch prison staff. These professionals – from all levels and with different disciplines (e.g., health care) – had no experience with facilitated moral reflections.
In order to assess the value of MCD in Dutch prisons, we implemented a series of 10 MCD-sessions with 16 teams of 3 prisons; 131 MCD-sessions were included. We used multilevel quantitative analysis and qualitative analyses of two self-developed questionnaires; after individual MCD-sessions and after a series of MCD-sessions. We received 871 MCD evaluation-forms (19 closed -, 5 open questions) of MCD-participants from individual sessions. We received questionnaires before (n=459) and after the series (n=456) to measure the impact of MCD on their Moral Craftsmanship (MC). We first defined what MC exactly entails, and we included a control group of teams from 3 additional prisons whom during the research period did not receive any type of facilitated moral reflection. This questionnaire had 70 closed items on MC, and the after-measurement additionally included 9 evaluative-items on MCD.
After the MCD-series, prison staff are more willing to ask questions about the 'why' of decisions made by colleagues and managers. Compared to the control group, after MCD prison staff engage more with their supervisor when the supervisor does something they do not think is right. And the MCD-participants as well state they experienced complex situations as less difficult to handle than the control group. Additionally, qualitative results show an improvement in experienced empowerment and/or self-confidence of participants after MCD, e.g., due to a better understanding and substantiation of their courses of actions.
The outcomes show a positive impact of MCD on a few items of the moral craftsmanship of prison staff. However, to increase the potential impact of MCD our data showed attention is needed for the influence prison staff actually have in practice, to be able to translate results of MCD-session into concrete actions which lead to visible changes in practice.

(34) Title: Online Moral Case Deliberation. An acceptable or undesirable form of Clinical Ethics Support?

Authors: Dr. Margreet Stolper (Assistant Professor, Amsterdam UMC), Dr. Janine de Snoo-Trimp (Post-doc, Amsterdam UMC), Suze Mathilde Stuurman (junior researcher, Amsterdam UMC), Patricia Dijkstra (student-assistent, Amsterdam UMC)

Abstract:
Background: During the Covid-pandemic, Clinical Ethics Support (CES) services were forced, like many other professions, to look for alternatives ways to offer their support. In The Netherlands, it resulted in online moral case deliberation (MCD) sessions as a common yet new practice. But is this an adequate form of CES and what are the differences in the process and outcomes between a meeting in which participants and the facilitator are physically present? Is it feasible to foster an online dialogue and joint reflection among participants? What are the pro's and con's of online MCD?

Method: In the past year, we conducted research to see whether this form of ethics support would be a permanent post-Covid and additional form of CESS. With a questionnaire among participants and facilitators and a focus group with facilitators, we looked into the experiences with and the impact of online MCD.
Findings and conclusions: In this presentation we will share our preliminary findings, insights and conclusions regarding if, when and how the online form of MCD could or should be a permanent new form of CES.

(35) Title: Financial incentives in public health: An ethical review

Authors: Roshni Jegan, PhD Researcher, Center for Biomedical Ethics and Law, KU Leuven; Kris Dierickx, Professor, Center for Biomedical Ethics and Law,KU Leuven

Abstract:
Enabling people to adopt healthy behaviour can save many lives. To this end, different methods of health promotion have been adopted over the past few decades. One such approach involves the use of incentives in public health, where an incentive refers to a reward that can motivate individuals to attain a desired health-related goal.
Although incentives can take many forms, financial incentives are among the most commonly used. Diverse health-related activities such as vaccinations, medication adherence, weight loss, smoking cessation, adequate antenatal visits and in-hospital childbirths have been subject to incentivization. At the same time, healthcare workers can also be rewarded based on the volume or quality of services they provide, as seen in Pay-for-Performance or P4P schemes.
Although behavioral economics supports the use of these rewards to motivate healthy behavior, questions remain concerning the ethical acceptability of incentives. Tensions exist regarding whether incentives are manipulative or coercive, whether they can corrupt motivations, and regarding fairness, equity, distributive justice and sustainability. For policy makers in public health, it is important to understand these ethical tensions while designing and implementing incentive-based programs.
In order to critically evaluate and map the existing ethical tensions of using incentives in public health, we conducted a systematic review of reasons, which identified 43 relevant articles. We will first identify all ethical reasons for and against the practice, and then highlight the existing gaps in literature. We show how ethical principles such as upholding autonomy, ensuring equity and preventing harm can both support as well as refute incentive programs for health. In addition, we show how ethical tensions vary based on the socio-economic context, the value and framing of the incentive, whether it is targeted at specific groups and the kind of behavior change that is incentivized.
In the conclusion section, we highlight the implications for Public Health.

Parallel Session 2
Room: 7TM
Chair: Renzo Pegoraro

(36) Title: Systematic reviews in bioethics: a problematic addition to bioethics methodology

Authors: Giles Birchley, Research Fellow, Centre for Ethics in Medicine, University of Bristol; Jonathan Ives, Professor of Empirical Bioethics, Centre for Ethics in Medicine, University of Bristol

Abstract:
Bioethics may be, like Kant's description of metaphysics, a "battle-ground … where no participant has ever succeeded in gaining so much as an inch of territory". Kant might therefore have approved of attempts within bioethics to make more definitive progress by using systematic reviews in bioethics research. However bioethics, while multidisciplinary, uses broadly philosophical methods of argument in its outputs. The term 'systematic review' comes with much unhelpful conceptual baggage, implying an objective scientific standard that is completely unsuited to bioethics.
Taking the Cochrane Handbook's definitive model of systematic review as our starting point, we argue the individual stages are either problematic or impossible for bioethics reviews to replicate. The contents of bioethical sources are explicitly evaluative, and so notions of quality and bias associated with systematic review are inapplicable. Innovations that seek to group, classify and quantify arguments within bioethical sources pay too little attention to the fact that conceptual classification is argumentative and evaluative, since it is subject to 'typicality effects'. Any review in bioethics, by whatever method, is itself a process of argument that cannot aspire to neutrality. It is therefore at variance to the objective standard (however unachievable) suggested by the label of systematic review. Any 'systematic review' of ethical arguments in bioethics thus falls short of its name.
Having established that bioethics cannot hope to replicate the standards of systematic review, we conclude by considering the potential impact of overtly describing bioethics review as "systematic review". We suggest that any notional benefits to bioethics in terms of increasing impact and influence are likely to be offset by the inherent risks of misrepresenting bioethical arguments as definitive. While we agree that areas of inquiry need thorough and informative literature reviews, and that efforts to bring transparency and systematic methods to bioethics are to be welcomed, we conclude that the contents of bioethical articles are simply not suitable to be aggregated using the methods of systematic review, and that we should abandon the nomenclature of 'systematic review' in favour of a less misleading label.

(37) Title: How disruptive innovation fuels dialogue on the future and the foundations of bioethics: A meta-ethical revival in bioethics?

Authors: Dr. Seppe Segers (Bioethics Institute Ghent & METAMEDICA, Ghent University)

Abstract:
Medicine is one of the fields where disruptive innovations may not only impact praxis itself (i.e. how healthcare is delivered), but also how moral problems within this domain can be studied. The dominant framework to study such moral questions in the medical field today is commonly referred to as 'principlism'. This approach that was developed by Beauchamp and Childress, has been self-characterized by its architects as a theory committed to a 'global bioethics', indicating that its fundamental principles are not merely local or cultural, but universally applicable. Yet, in response to anticipated disruptive innovations (like health wearables, mHealth technology and AI-driven medicine), established principles of that framework – particularly respect for autonomy – have been put forward as concepts in need of revision. It is, more specifically, doubted whether those principles are up for the challenges ahead. I will argue that such criticism is not a fundamental problem for principlism, but rather an invitation to exemplify its metaethical commitments. That is, I believe that disruptive innovation may not so much disrupt ethics by disqualifying principlism as a method for studying moral problems in the medical domain, but that it may rather corroborate principlism's own metaethical roots in coherentism, which itself centers around revision and

specification of concepts and principles. In other words, while the emergence of principlism as a method in bioethics originated in part from a markedly array of technological developments paired with an apparent turning away from metaethical questions, the current wave of technologically disruptive innovations and the associated question for revising established ethical principles, may instead reanimate a metaethical focus on the coherentist foundations of principlism.

(38) Title: A Global Ethics Framework for the Evaluation of Health Technology Innovation

Authors: Tijs Vandemeulebroucke PhD - Sustainable AI Lab, Institut für Wissenschaft und Ethik, Rheinische Friedrich-Wilhelms-Universität, Bonn, Germany; Yvonne Denier PhD - Centre for Biomedical Ethics and Law, KU Leuven, Belgium; Chris Gastmans PhD - Centre for Biomedical Ethics and Law, KU Leuven, Belgium

Abstract:
Health technology innovations are shaping the presence and near future of healthcare in many ways and with an exponential speed. Technologies, among others robotics, artificial intelligence, nano-technology, biobanking, gene-editing, impact our experiences of health, disease, care, etc. As such, there is a growing consensus, both academically as societal, that these innovations need to be governed by ethical reflection. Fortunately, interest in and the recognition of the importance of health technology assessments, and the ethics dimension herein, has increased in the last decennia. Although this positive dynamic merits praise, this methodology is characterized by an almost exclusive focus on the use of technology in healthcare as detached from it societal embeddedness. Consequently, many ethical issues arising in the design and the development phase of a health technology innovation and outside a specific healthcare setting remain undisclosed (e.g. environmental impact, labor conditions during development).
In this presentation, we will present a new framework for the ethical evaluation of health technology innovations that we developed during a two-year (2020-2021) research project. Grounded in the insights of a systematic literature review of existing ethics frameworks and in an iterative, multi-phased and multi-stakeholder study, the framework challenges the narrowness of existing ones. Stakeholders belonged to one of three citizens categories: (a) general public (e.g. citizens, citizen groups, patients and users, informal caregivers); (b) care and technology professionals (e.g. health professionals, ethicists, lawyers, engineers, professional groups); (c) policy makers (e.g. politicians, advisory committees, legislative bodies, policy making organisations).
The framework exists out of a question matrix in which each question embodies an ethical principle or value. The framework covers three stages of the health technology life's cycle: design, development, and use/after-use. Moreover, it covers four integrated levels of possible ethical impact of the health technology innovation: global, societal, organizational and individual-relational level. Finally, the framework is meant to be used in a deliberative and collaborative spirit, including all relevant stakeholders (e.g. healthcare workers, patients, companies, ICT-engineers, environment representatives). Hence, bringing these four components into an ethical framework to evaluate health technology innovations meets the all-encompassing nature of these innovations.

(39) Title: Defying the dangers of dialogue: How the pandemic seduced bioethics towards moralism

Authors: Professor Ralf J. Jox, MD, PhD

Abstract:
During the Covid-19 pandemic, many moral questions have been intensely debated in the public, and morality has played a pivotal role in political decision making. The aim of this theoretical scholarly work is to critically analyze the way moral issues have been treated during the pandemic and the role bioethics has played in them. Methodically, this work is based on philosophical reflection, using an analytic approach and anchor examples in order to disentangle different phenomena and suggest hypotheses about their relatedness. My main thesis is that the pandemic has accelerated and intensified the development of public moralism, which has originated already before the pandemic and has to do with identity politics in a postmodern society. Moralism is characterized by three hallmarks: (1) An extension of moral judgments to previously non-moral issues; (2) a simplification of moral judgments to binary, often antagonistic choices; and (3) an antirationalist, affective approach to moral judgments that uses the rhetoric of guilt and shame. Moralistic discourses and decisions have dominated the pandemic because of the existential angst of people, the overburdening complexity of scientific information in an area of huge uncertainty, and the insufficiency of personal and collective resilience and resources to rationally deal with these moral decisions. Bioethicists have been tempted to align with the moralistic mainstream, whereas their role would have been to guard against the false route of moralism. The antidote to moralism is an enlightened form of ethics, intrinsically bound to real dialogue, and it is therefore the major current task of bioethicists to exemplify such an ethical approach in a responsible, humble, and self-critical way.

Parallel Session 2
Room: 8TM
Chair: Dario Sacchini

(40) Title: Intersectional feminist virtue ethics of medicine – Kindness, caring and empathy as virtues to just medicine and health care

Authors: Dr. Merle Weßel, PostDoc, Carl von Ossietzky University of Oldenburg

Abstract:
The pluralisation of societies makes the injustice and inequality experienced by marginalized groups more visible. This issue arises also in medicine and health care where diverse and marginalized people form a particular vulnerable group. Justice and equality for people with diverse identities in context of access to health care but also their experience of health care and medicine constitutes an important ethical challenge. They are often based on multidimensional discrimination, as it is formulated in the feminist theory of intersectionality. Intersectionality, originating in Black feminist thought, argues that some forms of discrimination cannot be understood in one-axis terms, such as racism or sexism, but must be seen as an intersection of multiple social categories, such as race, gender and class. Medical and bioethical approaches have engaged in intersectional discussion but it is yet to be determine if intersectionality can be understood as own ethical theory or as framework checker of existing ethical theories.
Based on this unclear framing of intersectionality in medical and bioethics so far, I examine the question what intersectionality has to offer to medical ethics and also what intersectionality can learn from medical and bioethics to contribute to discourses of just medicine and health care. Firstly, I critical review the current stage of discussion on intersectionality in medical and bioethics to demonstrate that current approaches do not grasp the full potential of intersectionality for medical and bioethics yet. Secondly, I discuss if intersectionality indeed is an agent-centred, such as virtue ethics, and not

action-centred approach, such as deontology or teleology, due to its focus on non-discriminatory behaviour of individuals and its interaction with structural discrimination. Finally, I propose an intersectional feminist virtue ethical framework with the leading virtues of kindness, caring and empathy arguing that these virtues provide healthcare practitioners with the ability to understand the diversity of their patients as well as the effects of diversity on their health. This approach generates normative principles based on intersectionality taking power imbalances into account and contributes to justice and equality in medicine.

(41) Title: In a different orientation: health, values, and sexuality in dialogue

Authors: Emanuele Mangione, PhD student, Department of Biotechnology and Science of LIfe, Center for Clinical Ethics, University of Insubria

Abstract:
Despite recommendations within the mental health fields for affirmative, multiculturally competent and client-centered approaches in the treatment of individuals distressed by their same-sex sexual attractions, relatively little is known of which cognitive and emotive strategies should be adopted for an actual psychotherapeutic intervention. Lesbian, gay male, and bisexual individuals still tend to struggle to have well-integrated personal and social identities, especially when they perceive an irreducible conflict between their sexualities, on the one hand, and their ethics or religious faiths, on the other. Based on the ethics of care and the paradigm of relationship-centered care, this paper first considers the feelings of anger, confusion, suicidality, and the other negative mental health consequences frequently related to this conflict, and hence explores how a clinician might take care of someone who is ethically or religiously conflicted by their sexual orientation. With the aim to respond to this ethical quandary and balance the principle of beneficence and scientific evidence on sexual orientation with the principle of autonomy—including the principle of respect for aspects of human diversity such as religion—, clinical case reports are analyzed, and three possible general response strategies are inductively obtained: the hypothesis is that, alongside a first strategy which would prioritize values over sexualities (i) and a second strategy that would prioritize sexuality over values (ii), there might be a third more appropriate strategy which chiefly focuses on the relationship between the client and their care provider (iii). Once delineated, these three strategies are discussed alone in their specific characteristics, and then they are compared in their potential health outcomes for the individuals involved. Finally, it is suggested that the third strategy (iii) may be particularly worthwhile for increasing the health of the individuals involved, since it would not only prioritize a predetermined outcome, but—assuming multiple identities as not dichotomous—it could also facilitate the dialogue between them, in a way which could be consistent with scientific evidence and multiculturally inclusive at the same time.

(42) Title: The Religious dimension of Bioethical debates in Russia: the case of IVF

Authors: Authors: Roman Tarabrin, MD, MST, Researcher, Privolzhsky Research Medical University, Nizhny Novgorod, Russia.

Abstract:
The Russian Orthodox Church was mostly silent during the Soviet era due to the totalitarian regime's restrictions. After the collapse of the Soviet Union and the gaining of religious freedom, emerging medical technologies became an issue that demanded a response from the church. Subsequently, the Russian Orthodox Church published a bioethical position in a document entitled "The Basis of the Social Concept." However, lacking experience in the public sphere, the church did not provide sufficient detail and clarity on bioethical issues. Some unclear statements even led to controversy in Russian society. The ambiguity could have been resolved through a larger discussion involving a broader range of experts and by clarifying the reality of medical practice. However, the religious discourse of bioethics in Russia in the 1990s was confined to a limited number of people (including some bishops, priests, and theologians).
Around the 2010s, heated debates regarding reproductive technologies began, initiating a change in the church's decision-making strategy regarding bioethical issues. The church began to recognize a socio-cultural shift in Russian society. For example, more people began to seek treatment for infertility through in vitro fertilization. To avoid division among her followers, the Russian Orthodox Church requested the Orthodox community's opinions to preserve the connection between bishops and their congregations. Thus, bishops started requesting input from parish priests and lay believers to shape future bioethical policies. This mechanism for incorporating the feedback of ordinary people and priests throughout Russia was implemented via the Inter-Council Presence department. The ongoing discussion of the acceptability of in vitro fertilization in Orthodox discourse has demonstrated how significant bioethical issues are in the lives of religious people.
Thus, in the 2020s the Russian Orthodox Church replaced the previous authoritative approach to tackling bioethical issues and initiated open discussion with members, thereby attempting to find mutually acceptable bioethical solutions and helping people to fulfill their religious tenets while using new medical procedures.
Keywords: Christian bioethics, Russian Orthodox Church, In Vitro Fertilization, Inter-Council Presence Department.

(43) Title: Report on methodology and results of Intercultural and Interreligious dialogue in Bioethics

Authors: Joseph Tham, LC, PhD, Regina Apostolorum Pontifical University, Rome, Italy

Abstract:
For the last ten years, the UNESCO Chair in Bioethics and Human Rights has been involved in a project of "Bioethics, Multiculturalism and Religion". Seven international workshops have been held in Jerusalem (2009), Rome (2011), Hong Kong (2013), Mexico City (2014), Houston (2016) Rome (2017) and Casablanca (2019). These academic encounters had gathered scholars in bioethics and religious ethics from the major world religions—Buddhism, Christianity, Confucianism, Daoism, Hinduism, Islam, Judaism—as well as the secular perspective. The great diversity in opinions, positions based on the variety of cultural and religious traditions has been very enlightening and challenging. In these encounters, we have been experimenting with different modalities of interaction and conversation. The methodology is still evolving, and we are working out an approach that allows for both expressions of diversity of opinions while avoiding relativism. In this presentation, we will provide some statistics of these encounters, and report the results of these interactions. The successes and pitfalls we have observed in these workshops will be valuable for those who are interested in the area of interreligious and intercultural engagement in bioethics.

(44) Title: Is religious contribution possible or needful for contemporary bioethics? Reflection from the perspective of the fifty years long Catholic engagement in Bioethics.

Authors: Branka Gabric, PhD, Insitute for the Global Church and Mission, Philosophical-Theological University Sankt Georgen

Abstract:
Catholic Church has a very elaborated approach to all classical bioethical questions. It was one of the religious institutions engaged in bioethics since the very beginning of the discipline in late 1970. However, often Church's teaching and approach regarding these topics is perceived as conservative and is non-rarely initially rejected because connected with the religious beliefs.
This contribution will discuss the question of the religious communities and their bioethical approaches, taking as an example the Catholic Church and its dialog with other bioethical orientations. We will ask whether all bioethical approaches coming from religious communities should be rejected at the outset in the name of the secularity of bioethics and how one can judge which approaches are "fundamentalist". Is this strong description used exclusively for directions coming from religious backgrounds?
The focus will be on the discussion of whether the contribution of bioethics that comes from a religious background is possible and what would be the prerequisites for the dialog or even collaboration between bioethics from the religious and non-religious milieu.

Parallel Session 2
Room: 9TM
Chair: Pietro Refolo

(45) Title: The reception of A. MacIntyre's thought in Health Sciences

Authors: David Lorenzo, Full Professor of Ethics, Borja Institute of Bioethics and Campus Docent Saint John of God, Barcelona

Abstract:
Alasdair MacIntyre is one of the most important authors in contemporary Ethics and Political Philosophy. Regarding his political thought, he was a key figure in the Liberalism Communitarianism debate, one of the most important and fruitful in the field of Moral and Political Philosophy in the second half of the 20th century.
Beyond Ethics and Political Philosophy, many concepts of his thought (such as 'virtue', 'practice', 'community' or 'tradition') have been used by other fields of knowledge such as Education, Economics, Business, Management... And also Health Sciences (Bioethics, medicine, nursing, etc.) have taken these concepts to apply them to clinical theory and practice.
This presentation deals with the reception of A. MacIntyre's thought in the field of Health Sciences, in the field of health care (medicine and nursing). A detailed analysis of this reception allo0077s us to see that the concepts and works of MacIntyre that have influenced more in the field of health sciences can be divided into two groups.
1st) The concepts of 'practice', 'virtue', 'narrative unity' and 'tradition', taken from the book "After Virtue", published in 1981.
2nd) The concepts of 'vulnerability', 'dependence' and 'virtue (of giving and receiving)', taken from the book "Dependent Rational Animals", published in 1999.

(46) Title: Moral psychology and bioethics: A challenge to the value of autonomy?

Authors: Giles Birchley, Research Fellow, Centre for Ethics in Medicine, University of Bristol

Abstract:
Preference satisfaction is the zeitgeist of post-war policy, and under the influence of bioethics, the heart of pragmatic approaches to medical decision in law and clinical ethics. While these approaches require a simplification of autonomy to equate it to preference, such a simplification seems valid if, as many in bioethics argue, i) humans have the best understanding of their own condition and ii) they will ultimately take rational decisions about it. Defending preferences in this way is the foundation of many of the philosophically influenced innovations of bioethics. However, the empirical picture painted of moral behaviour in moral psychology challenges suppositions of both rationality and introspection.
Moral psychology applies existing or new experimental data from psychology to understand human moral behaviour in controlled conditions. Moral psychology has developed insights into a vast array of areas relevant to ethical inquiry, including insights into the way moral judgements are formed and the level of introspective insight people have into their actions. Particularly salient to bioethics are findings from moral psychology that suggest that, far from being based on the insightful application of rationality, human moral behaviour is largely based on affective triggers, that humans lack insight into the causes of our behaviours, although they do have a marked ability to conjure narratives to fit observed facts. Such findings radically challenge many of the dearest values of bioethics.
This presentation considers the evidence from moral psychology and asks both how bioethics can respond without undercutting its empowering mission. A belief that our lives are dictated by a free exercise of preferences can make a fundamental contribution to human wellbeing, however it commits and injustice if creates expectations of responsibility and rationality that are beyond our human reach. How we navigate this tension may require a reframing of bioethical approaches.

(47) Title: Telemedicine and clinical ethics. A philosophical contribution

Authors: Monica Consolandi, Ph.D. Student, Università Vita-Salute San Raffaele

Abstract:
The aim of the paper is to highlight the way in which telemedicine affects doctor-patient relationships, shedding light on its positive and negative aspects from a philosophical perspective. I will apply tools from the philosophy of language to stress out the importance of being aware of the repercussions of virtual interactions on the therapeutic relationship.
Studies show the rise of digital technologies during the pandemic in the European context and all around the world. Telemedicine presents positive outcomes in terms of sustainability with respect to chronic patients. However, it must be considered the way in which it affects doctor-patient relationship, both in terms of building a strong therapeutic alliance and of communicative effectiveness.
Philosophy of language relates primarily with this second point, but strongly influences also the first one. I will analyze if and how telemedicine shows itself to be the best way to take care of patients. The "if" may be declined in terms of i) clinical criteria: the patients' clinical conditions; ii) relational criteria: patients' preferences and skills; and iii) equity: patients' access to technologies. The "how" is the crucial focus of the paper: once established that telemedicine is the right tool to be used, we must ask ourselves how to decline it to make it as effective as possible. I will show what are the philosophical tools to be applied and how they can help us in make telemedicine successful. Verbal and non-verbal communication, symmetry and asymmetry in the doctor-patient relationship, silence and pauses, and persuasion are important subjects of study in philosophy of language that show themselves to be relevant in the context of telemedicine. It is worthy to reason about telemedicine with philosophical and linguistic tools to improve its implementation in terms of building a shared space, and properly use metaphors, implicit, and creativeness. This would allow to improve patient-centered medicine in the virtual context.

Considering the "if" and the "how" would help healthcare professionals in better understanding the best way to manage telemedicine. It would be helpful to consider revising the medical curriculum to build communicative competences in relation to these sensitive tools.

(48) Title: The figure of "S'accabadòra" and the fate of the dying. Perceptions from a historical, anthropological, and bioethical reasoning.

Authors: Roberta Fusco, Centre of Research in Osteoarcheology and Paleopathology, Department of Biotechnology and Life Sciences, University of Insubria, Varese, Italy, Chiara Tesi, Centre of Research in Osteoarcheology and Paleopathology, Department of Biotechnology and Life Sciences, University of Insubria, Varese, Italy, Giovanni Rasori, Phd student, Department of Biotechnology and Science of Life, Center for Clinical Ethics, Insubria University, Emanuele Mangione, Phd student, Department of Biotechnology and Science of Life, Center for Clinical Ethics, Insubria University, Mario Picozzi, Director of the Center for Clinical Ethics, Biotechnology and Life Sciences Department, University of Insubria, Varese, Italia

Abstract:
Whatever its forms, medical practice is inextricably rooted in a particular societal context. As a result, physicians must respond to various societal requests, face some specific economic or political pressures, and abide by the laws of their country; however, since they are physicians they must respect their professional duties as well, so that there could be a conflict between their duty to preserve their moral and professional integrity and their duty to respect the different values of their patients and, more in general, of their societal context. Considering this within the Italian socio-legal context, this paper explores the little-studied hypothesis of a physician substitution: since physicians cannot perform some acts such as euthanasia because they are supposed to be contrary to medical ethics, then these acts might be performed by a non-physician.
Insights on this issue come from historical research, which can make us question about the current bioethical discussions. Retracing the history of Sardinia, the controversial figure of the "accabadòra" emerges. According to the common conception, S'agabbadòra was a woman who was called to put an end to the agony of the dying. It was the family or the dying himself who requested her intervention, invoking a "good death". The act took place according to a pre-established ritual approved by the whole community that recognized in it a social utility. For this reason, whoever materially carried out the gesture was not considered a murderer, but a person who, in the name of the whole community, took on the task of alleviating the passing away.
In this contribution we will address the current bioethical discussion by providing a cross-cutting point of reflection of historical origin and investigating the complex figure of the accabadora as the bearer of a kind of euthanasia that can be defined "ante-litteram".

(49) Title: Earnest Bioethics. Dialogue in the Spirit of Kierkegaard

Authors: Vilhjálmur Árnason, professor, Centre for Ethics and Department of Philosophy, University of Iceland

Abstract:
In this paper, it is asked what it implies to do bioethics in the spirit of Kierkegaard. The response to this question is fleshed out in the form of reflections on two aspects of his thought that I take to be of major relevance for bioethics: the mood of earnestness and the art of helping. First, I inquire into what it means to do biomedical ethics with the earnestness which Kierkegaard said to be the proper mood for ethical thinking. This is demonstrated via negativa, by arguing that this entails engaging with ethical issues in a manner that is different from some prevailing modes of reasoning in bioethics. Prevailing argumentations in bioethics exemplify playing aesthetically with possibilities without showing the subject matter the kind of respect it requires. This often characterizes instrumental, monological reasoning which results in partial moral blindness since it loses sight of matters that are of profound moral significance. The mood of earnestness is also relevant for teaching biomedical ethics, which should inspire the type of engagement and spirit required for properly handling ethical questions. For Kierkegaard, it is not so much the dissolving power of argumentation as the maieutic birth of ideas in the individual, signifying the importance of Socratic dialogue in this context.
Further, it is argued that Kierkegaard's notion of the art of helping has implications for the patient-professional relationship that must be articulated in other categories than the dominant bioethical discourse. In Kierkegaard's dialogical approach, the primary duty of the helper is to bring the person in need to the desired outcome, calling for clear guidance. Engaging authentically in a conversation with the person in need, the helper must take care not to lose sight of this end. I argue that this places duties on healthcare professionals which are in tension with the dominant views found in the bioethical literature and cannot be properly articulated in the terminology of patient autonomy and paternalism.

Parallel Session 2
Room: 1PM
Chair: Francesca Greco

(50) Title: "Infections stories" - using Bram Stokers Dracula (1897) to reframe moral distress in the Corona crisis

Authors: Cand Dr. med. Laura Biondi and Prof. Dr. Rouven Porz, Medical Ethics Unit, Bern University Hospital, Medical Faculty Bern, Switzerland

Abstract:
The Covid-19 pandemic has hit clinical practice hard. Sometimes it was difficult to talk about the same topics again and again in the context of clinical ethics support, e.g. uncertainty, moral distress, fear of triage, unclear handling of those patients who do not believe in corona or science or are unvaccinated. It sometimes helped to take a mental detour. Thus, we have often taken this detour in ethical case discussions and continuing education with reference to Bram Stoker's Dracula (1897). We would like to illustrate this helpful "triangulation" (Hub Zwart, 2019) in our presentation as a helpful and innovative tool of clinical ethics support.
The methodological background is the idea that literature can serve as a backdrop for coming to terms with the present. The aim is to understand Covid-19 as a phenomenon via "triangulation": a methodological technique which examines a current phenomenon by comparing it to something else which is both relevant but also distant. Via this technique, the entanglement between us and the phenomenon at hand is opened-up, allowing us to zoom out and in, studying the phenomenon from a broader perspective. This procedure can help to reduce moral distress. Dracula is particularly suitable because almost everyone (consciously or unconsciously) has images of this story, and besides, at first hardly anyone suspects a connection between Covid-19 and a vampire's story.
It will turn out that there are surprisingly many starting points for triangulation between us, Bram Stokers Dracula and Covid-19, especially in relation to superstition, science but also in relation to social injustices and different local contexts.

(51) Title: Meeting of ethics and design methodologies for a pragmatic and reflective approach to bereavement situations in nursing homes during the COVID-19 pandemic

Authors: Noémie Chataigner (PhD student in Ethics and Design, Université Paris-Saclay), Jean-Philippe Cobbaut (Director of Centre d'Éthique Médical, Université Catholique de Lille, Doctor HDR in Public Health)

Abstract:
The context of the COVID-19 pandemic brought painful experiences in nursing homes, due to numerous experiences of mourning and loss while the practices of accompaniment were impeded by the protective measures put in place.
The action research in ethics and design on which our communication could focus was initiated by a request from professionals working in nursing homes for whom this health rationalization has weakened the ethical intuitions of support practices. The action research is based on a contextual and collaborative investigation that brings together the nursing home actors and two disciplines, ethics and design. We would like to present the results of a collaboration between ethics and design based on the device designed, a material device that seeks to provide a collective capacity to cope with bereavement situations. We would like to consider how these two disciplines allow for a reflective and pragmatic approach to the context and experiences, as well as for putting them into action.
Design is a project discipline whose social approaches, through immersion and co-design, consider in a caring manner the stakeholders of a situation, their experiences and the material context. The pragmatic and contextual approach to ethics gives an important role to the stakeholders involved in that it engages them in a process of inquiry through the understanding of the problems encountered and the determination of common directions which would enable them to resume the course of action. Here, design allows for the conception of a material device that makes this commitment effective.
This common attention to actors and contexts allows the methodologies of ethics and design to respond to each other and to be built in complementarity as the research progresses. We could mention how ethics maintains open reflexivity on the methodologies and tools of design, on the interpretation of contexts and the place given to actors, by considering the very ethical nature of this design process. In a complementary way, design reinforces a pragmatic approach to ethics, notably by completing its narrative approach with an attention to devices as sources of experience and by the materialization of responses to the situation considered.

(52) Title: Justification and implementation of prioritization criteria in cancer care in the context of the COVID-19 pandemic. Findings from structured group discussions

Authors: Sabine Sommerlatte (Institute for History and Ethics of Medicine, Interdisciplinary Center for Health Sciences, Martin Luther University Halle-Wittenberg, Halle, Germany), Helene Hense (Center for Evidence-based Healthcare, University Hospital and Medical Faculty Carl Gustav Carus, TU Dresden, Dresden, Germany), Celine Lugnier (Department of Hematology, Oncology and Palliative Care, St. Josef-Hospital, Ruhr-University, Bochum, Germany), Anna-Lena Kraeft (Department of Hematology, Oncology and Palliative Care, St. Josef-Hospital, Ruhr-University, Bochum, Germany), Olaf Schoffer (Center for Evidence-based Healthcare, University Hospital and Medical Faculty Carl Gustav Carus, TU Dresden, Dresden, Germany), Thomas Birkner (Center for Evidence-based Healthcare, University Hospital and Medical Faculty Carl Gustav Carus, TU Dresden, Dresden, Germany), Jochen Schitt (Center for Evidence-based Healthcare, University Hospital and Medical Faculty Carl Gustav Carus, TU Dresden, Dresden, Germany), Anke Reinacher-Schick (Department of Hematology, Oncology and Palliative Care, St. Josef-Hospital, Ruhr-University, Bochum, Germany), Jan Schildmann (Institute for History and Ethics of Medicine, Interdisciplinary Center for Health Sciences, Martin Luther University Halle-Wittenberg, Halle, Germany)

Abstract:
Background: The COVID-19 pandemic has brought the discussion of equitable distribution of medical resources into the public spotlight more than ever. Many areas, including cancer care, were affected by limitations such as a temporary reduction in surgeries and a decline in screening and aftercare measures. Long-term effects of the pandemic on cancer patients can only be assessed based on data analyses in the coming years. However, transparent, empirically and ethically informed prioritization criteria in situations with potential resource scarcity are crucial for the equitable allocation of health resources and the treatment safety of the team as well as the patients' trust in the healthcare system.
Methods: We conducted four online group discussions between January 20th and February 15th 2022 with experts from different disciplines to discuss criteria for priority setting in cancer care during pandemic as well as their rationales using the example of gastrointestinal tumors. Participants were recruited by direct approach using the purposive sampling method. Structured discussions were held on three topics: 1. diagnostics and screening, 2. surgical capacity, system and radiation therapy, and 3. psychosocial and palliative care. Transcripts of interviews are analyzed following principles of qualitative content analysis based on Kuckartz.
Results: 22 experts from medicine (n=13), nursing (n=2), law (n=2), ethics (n=2), health insurances (n=2), and health services research (n=1) participated in the study. Structured discussions lasted 1.5 hours. The following prioritization criteria were discussed: Urgency (e.g. prognosis, symptom burden, presence of risk factors), chance and criteria of success (e.g. survival, quality of life), patient preferences and availability of alternative treatment options. Criteria considered unacceptable were e.g. disability and social characteristics. Further topics discussed were the need to strictly apply evidence based guidance and reduction of overdiagnostics and overtreatment.
Conclusion: While the criteria addressed in the group discussions are familiar from the ethical debate their application with regard to specific guidance on prioritizing specific diagnostics and treatment proved to be a challenge. In our presentation we will explore these challenges and possible implications based on the ongoing process of developing the national guideline "Prioritization and Resource Allocation in the Context of the Pandemic".

(53) Title: The Maximin Rule under the COVID-19 Pandemic: A Thought Experiment with Regional Triage Model

Authors: Jun Tokunaga, MD., PhD, Sayama Neurological Hospital (Japan)

Abstract:
The COVID-19 pandemic has triggered a debate on whether triage constitutes discrimination. From the standpoint of consequentialism, the theory of triage, which determines the priority of lifesaving measures, leads to the conclusion that patients with a high chance of survival should be prioritized, without simultaneously discriminating against the elderly or patients with underlying diseases. Based on the principle of maximizing the number of lives saved, it is easy to form a consensus that is useful in guiding medical practice. However, existing theories disregard the role of politics and do not consider the variability of medical resources under the pandemic, thereby resulting in a kind of fallacy of composition concealing the discrimination caused by inadequate infection control. Triage in the pandemic is political and requires a different theoretical framework than the one for disasters or

accidents. In this study, we attempt to develop a theoretical model that deals with triage for the entire region, while considering the medical system from the perspective of the mildly ill to the severely ill as well as the time required for its preparation. The purpose of this study is to explore the landing point of the controversy over discrimination by conducting a thought experiment within the framework of consequentialism. In short, when the principle of maximizing the number of lives saved is thoroughly applied at the regional level, the expansion of medical resources based on the maximin rule, which prioritizes the vulnerable, becomes the most important ethical requirement. Ensuring the preservation of life under a pandemic is consistent with John Rawls' vision of justice emphasizing equality.

(54) Title: Ethics of rooming-in with COVID-19 patients: Mitigating loneliness at the end of life

Authors: R.L. van Bruchem-Visser, MD, PhD, Department of Internal Medicine, Erasmus Medical Center Rotterdam, the Netherlands; Eline Bunnik, Phd, Department of Medical Ethics, Philosophy and History of Medicine, Erasmus Medical Center Rotterdam, the Netherlands; S. Siddiqui, MD PhD, Department of Anesthesia, Critical Care and Pain Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA, USA

Abstract:
The COVID-19 pandemic is taking many lives around the world. When patients infected with SARS-CoV-2 become critically ill or are dying in hospitals, they must often make do without the physical presence of family members. Family visitation is commonly restricted based on safety concerns. Although spread of the SARS-CoV-2 virus should be prevented, and imposing limits on family visitation in hospitals may be instrumental to this end, separation of family members from critically ill patients is not humane. The moral costs of not being able to be together at the end of life may not outweigh the benefits of reducing risk of infection with SARS-CoV-2. Relaxation of family visitation policies in hospitals is therefore of paramount importance to patients critically ill with COVID-19 and their family members.

Parallel Session 2
Room: 2PM
Chair: Virginia Sanchini

(55) Title: How to ensure that the smart home stays a true home: Somatic design suggestions to ensure familiarity, stability and privacy for older residents

Authors: Nadine Andrea Felber, PhD Candidate, Institute of Biomedical Ethics, University of Basel, Dr. Hamed Alavi, Visiting Researcher, UCLIC, University College London, Dr. PD Tenzin Wangmo, Senior Researcher, Institute of Biomedical Ethics, University of Basel

Abstract:
Smart home technology has the potential to support older persons to age in place. However, older persons are not used to their home being technologically enhanced. They are used to experiencing their home and making decisions at home through their somatic experience only, without an external stream of data to influence these processes. We show how smart home technology potentially disrupts this experience of "home" for older persons. On the one hand, it disturbs the aspects of familiarity, stability and privacy, all crucial for the feeling of "home". On the other hand, it influences the so-called somatic capability assessment, a concept we propose to grasp how humans take decisions while relying on and listening to their physical body. In the last part of this essay, we will therefore propose design measures, inspired by the philosophical concept of somaesthetics, as well as a framework for the designing process, to enhance the aspects of familiarity, stability and privacy in the smart home and to support their somatic capability assessment, rather than challenging it, to therefore create an experience of "home" for older persons wanting to age in place.

(56) Title: Experiencing and handling ethical challenges in home-based service- an ethnographical study.

Authors: Cecilie K. Hertzberg, PhD student, Center of Medical Ethics, University of Oslo. Anne Kari Tolo Heggestad, Professor, VID Specialized University. Morten Magelssen, associate professor, Center for Medical Ethics, University of Oslo

Abstract:
What ethical challenges does employees in homebased service experience during a workday? And how are they handled?
Based on a nine- month long anthropological fieldwork in homebased service in Norway, I wish to explore the research questions stated above. The data collection is divided into three municipalities in the south of Norway and took place three months in each of the municipalities from September 2020 to November 2021. The fieldwork consisted of participant observation in both patient's home and the base of homebased service. In addition to interviews with patients and their next of kin, employees, and leaders.
The data collection indicates that employees in homebased service experience many of the same ethical challenges such as patient autonomy, coercion, and time pressure. However, the data also shows a variation of ethical issues. These are probably connected to people density and socioeconomic status.
The employees experience and handle and experience the ethical challenges differently according to which municipality they worked for. The data indicate that there are two main factors. The first is work environment and the second is leadership.
This is a draft of the first article in my PhD project and is still a work in progress.

(57) Title: Referral reasons of General Practitioners and Nursing Home Physicians for patients over 70 years old to the emergency department

Authors: R.N.E. Strijker, Bsc of Medicine, Erasmus MC, Rotterdam, Netherlands. R.L. van Bruchem-Visser, Phd MD, Department of Internal Medicine and Geriatrics, Erasmus MC, Rotterdam, Netherlands

Abstract:
Introduction: Elderly people are increasingly represented at the emergency department, while research has shown that hospitalization is not always the best option for the frail older patient. Earlier research only looks at emergency physicans and patient experience. In this study we examined the referral reasons of general practitioners, and nursing home physicians.
Methods: Referral reasons of general practitioners and nursing home physicians who send patients over 70 years to the emergency department of the Erasmus Medical Centre, Rotterdam, are explored. Research is done by conducting semi structured interviews, and

organizing focus groups. Interviews are transcribed verbatim and analyzed by using QRS NVivo 12 software. Ethical approval was obtained.
Results: Study is currently ongoing, results will be presented at the conference

(58) Title: Does pay for performance system turn physicians into estranged practitioners? A study on the physicians' perceptions of themselves as professionals, their moral stances, and their working and private lives under a new reimbursement system

Authors: Mustafa Volkan Kavas, Assoc. Prof., MD., PhD. Ankara University, Faculty of Medicine, Department of History of Medicine and Ethics, Ankara-Turkey; Hasan Tut, MD; 3rd author: Gamze Senyurek, MSc. Visiting Fellow, Amsterdam UMC, location VUmc, Department of Ethics, Law and Humanities, Amsterdam-Netherlands; Atilla Halil Elhan, Prof., Ph.D. Ankara University, Faculty of Medicine, Department of Biostatistics, Ankara-Turkey

Abstract:
Pay-for-performance system (P4P) has been in operation in the Turkish healthcare sector since 2004. While the government defended that it encouraged healthcare professionals' job motivation, and improved patient satisfaction by increasing efficiency and service quality, healthcare professionals have emphasized the system's negative effects on working conditions, physicians' trustworthiness, and cost-quality outcomes. In this study, we investigated physicians' accounts of current working conditions, their status as a moral agent, and their professional attitudes in the context of P4P's perceived effects on their professional, social, private, and future lives.
First, we held 3 focus groups with 19 residents and 1 specialist regarding their lived experiences under P4P and thematically analyzed the transcripts. Second, we developed a questionnaire in order to assess how generalizable the qualitative findings are for a broader group of physicians. The tool has three parts questioning 1) demographic information, 2) working conditions, and 3) perceived consequences and effects of P4P. 2136 physicians responded to the survey. After refining the data, we conducted the statistical analysis over 1378 responses by using Spearman's correlation coefficient, exploratory factor analysis (EFA) for categorical data, and Kruskal-Wallis variance analysis.
Thematic analysis revealed two dimensions: 1) factors leading to estrangement, and 2) manifestations of estrangement. As for the initial, participants thought that P4P affected relationships at work; family and social relationships; working conditions; quality of the specialty training; quality of healthcare services; and it caused healthcare system-related consequences. Concerning the latter, the following themes emerged: Estrangement of the physician; damaging effects on physician's psychology; physician's perception of their future life; and physician as a moral agent. According to EFA, a 5-factor structure was appropriate: F1) Estrangement; F2) adverse effects on the physician's quality of life; F3) favorable consequences; F4) physicians becoming disreputable; F5) unfavorable consequences.
The findings suggest that under P4P, physicians have become more estranged towards their profession, their patients, and themselves. They suffer from deteriorating working conditions, lack of motivation, lack of work-related satisfaction, and hopelessness regarding their future. Furthermore, P4P impairs their ability to realize themselves as moral subjects practicing in alignment with professional values and principles.

(59) Title: Equal access to healthcare in Poland: normative requirements and realities

Authors: Katarzyna Bielińska, Paweł Łuków, Center for Bioethics and Biolaw, Faculty of Philosophy, University of Warsaw

Abstract:
Article 68 of the Constitution of the Republic of Poland guarantees "equal access to healthcare services funded from public funds" to all, regardless their financial or other status. Following the judgement of the Constitutional Court (K 14/03), the constitutional right to equal access to healthcare does not depend on the persons' insurance status (K 14/03). Additionally, according to the same article, "special health care" shall be provided to "children, pregnant women, handicapped people and persons of advanced age." Therefore, public authorities are obliged to organize the healthcare system in a manner which would realize this constitutional principle of equal access.
This talk will present the results of the research conducted within the Project "Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe". We will analyze the level of realization of the equal access to healthcare in the Polish healthcare system on 1) legislative 2) institutional 3) practical levels. Special attention will be paid to the access to healthcare services of persons of such minority features as ethnicity, religion and belief, sexual orientation, and gender identity.
The project "Healthcare as a Public Space: Social Integration and Social Diversity in the Context of Access to Healthcare in Europe" is financially supported by the HERA Joint Research Programme (www.heranet.info) under HERA Public Spaces: Culture and Integration in Europe Programme (Hera.2.029) which is co-funded by the German Federal Ministry of Education and Research (BMBF); National Science Centre, Poland (Project No. 2018/28/Z/HS1/00554); Croatian Academy of Sciences and Arts; Slovenian Ministry of Education, Science and Sport and European Commission through Horizon 2020 (grant agreement No 769478).

Parallel Session 2
Room: 12MTG
Chair: Marta Spranz

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(60) Title: "There are just so many opportunities in digital health" – The politics of Data-driven Healthcare development in the Silicon Valley.

Authors: Bianca Jansky, M.A., Ethics of Medicine, University of Augsburg; Institute for Sociology, Ludwig-Maximilians-University, Munich

Abstract:
Data-driven healthcare technologies are increasingly being introduced into national healthcare policies. The development of these technologies is centered in geographical regions, most notably the so-called 'Silicon Valley' in the USA. These technologies carry the ideas and assumptions of those who develop them, and the regional setting where they are designed is significant, but often overlooked in discussions about Data-driven Healthcare. Recently there is a growing body of literature on how individuals are using these technologies in their everyday lives, and the ethical dimensions of the use are increasingly critically reflected upon in this context. In this presentation, I am going to zoom in on how the regional, political, and societal aspects and technology visions of the 'Silicon Valley'

are affecting how data-driven healthcare technology developers, designers, engineers, and other stakeholders think about their responsibilities and the technologies they design. Based on interviews and participatory observation in the Silicon Valley "Tech-scene" I retrace how these stakeholders are negotiating the societal values of the designed technologies, and the importance of the technologies they develop and are then used all over the globe in different healthcare contexts. I am going to use this empirical material to sketch out possible ways for bridging the gap between medical ethics scholarly discussions about data-driven healthcare technologies and these accounts on the experiences of stakeholders in the field.

(61) Title: Trustworthiness, reliability, and character: applications in the context of healthcare data institutions

Authors: Mark Sheehan (Associate Professor, University of Oxford), Mackenzie Graham (Senior Researcher, University of Oxford), Paige Fitzsimmons (PhD student, University of Oxford), Richard Milne (Senior Researcher, Cambridge University)

Abstract:
There currently is much discussion about trust and data use or access. Almost all of this discussion involves, in one way or other, institutions of one form or another. There are the standard scandals where there has been some kind of data breach or patient's data has been shared with or given to a commercial institution purportedly, so that it can be exploited for profit. One consequence of this talk is that research institutions, in particular, are very focused on securing their own situation. They want to make sure that they are trustworthy and that they are trusted.
Given that there is pressure on institutions, from both within and without, to be trusted (or to be trustworthy) it makes sense to begin to get clear about what it means for an institution to be trustworthy. Institutional trustworthiness is the endgame here: we orient our discussion towards understanding what it would be for a healthcare institution or a research institution or a commercial healthcare related institution to be trustworthy.
The paper proceeds by first outlining a few features of trust and trustworthiness that are particularly central in the philosophical debate. These features provide us with a platform to reflect on how we might begin to understand trustworthiness for institutions. The key features here are reliability and character – obviously in connection to their applicability to institutions. Both features, we think, cause significant problems for our task. The chief task in this paper is to set out these problems with perhaps a few gestures towards some solutions.

(62) Title: The Language of Trust in Health Data Sharing

Authors: Mackenzie Graham, Senior Research Fellow, University of Oxford; Mark Sheehan BRC Ethics Fellow, University of Oxford; Paige Fitzsimmons, DPhil Candidate, University of Oxford

Abstract:
Initiatives for health data sharing are increasingly being described using the language of trust. For example, the recent Goldacre Review commissioned by the UK's Department of Health and Social Care stresses the importance of 'building public trust' in health data sharing, a sentiment echoed by other policy papers and ethics guidelines from institutions across Europe.
A key aspect of the strategy to 'build public trust' in data sharing initiatives is responding to public expectations about what makes data users 'trustworthy'. Numerous surveys, public dialogues, and reports of patient and public attitudes towards health data sharing have shown that the public's willingness to trust data sharing initiatives is conditional on several factors, including privacy, transparency, public benefit, and accountability. Accordingly, data sharing initiatives are increasingly being designed to reflect public expectations regarding data security, transparency, and accountability (e.g., the move towards 'Trusted Research Environments' as the accepted platform for data access for research in the UK).
However, by emphasizing the importance of data security, transparency, and accountability, we actually move away from trust. This is because trust is fundamentally concerned with vulnerability; when I trust, I make myself vulnerable to the possibility that my trust will be disappointed or betrayed. Thus, in striving to eliminate the possibility that data will be misused, we strive to eliminate the need for trust in the first place.
I argue that policymakers need to be careful about appropriating the language of trust in the context of health data sharing. While describing health data sharing as 'trusted' or 'trustworthy' may be an effective means of garnering public support, I will argue that it also invites certain expectations about how the trusted person or institution will behave, as well as appropriate responses to their behaviour. Misalignment between these expectations risks undermining support for data sharing initiatives, the very thing that adopting the language of trust was meant to secure.

(63) Title: Trust and Trustworthiness: Health data and commercial organisations

Authors: Paige Fitzsimmons, PhD Student, University of Oxford

Abstract:
The notion that we, as a society, are experiencing a crisis of trust is both far reaching and common in colloquial discourse. In 2018, Secretary-General António Guterres opened the United Nations General Assembly with the statement "our world is suffering from a bad case of 'Trust Deficit Disorder.'" In healthcare today the rapid development and refinement of artificial intelligence and machine learning technologies, along with the widespread aggregation and use of patient health data for research, is seemingly inevitable. However, given the aforementioned crisis of trust, some form of public acceptance for the use and governance of access to health data by a variety of researchers and research organisations is essential if we are to realise the potential public health benefits of these developments.
In this presentation I argue that given the subjective commonality of the concept of trust, there is not one single account of trust or trustworthiness which can be applied in the case of health data. I will outline a variety of conceptual accounts of trust and trustworthiness and work through case examples of how these might apply in the context of health data access and use by commercial organisations in the UK. Relevant empirical findings to date will be presented and their coherence with the philosophical literature explored. I will also speak to the distinction between trust and trustworthiness and expand on why this distinction is more than just semantics.

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Friday, September 16th, 2022
Plenary Session 3: The dialogue with society and politics

Chair: Alessandra A. Grossi – Key lecture: Ana Borovecki (University of Zagreb, President ESPMH)



Ana Borovecki is Professor and the chair of the Department of Social Medicine and Organisation of Healthcare at Andrija Stampar School of Public Health, School of Medicine, University of Zagreb and a member of Centre for Palliative Medicine, Medical Ethics and Communication Skills, Faculty of Medicine, University of Zagreb (CEPAMET). She graduated at the Medical Faculty of the University of Zagreb and graduated in philosophy and comparative literature at the Faculty of Philosophy, University of Zagreb. She holds the degree of European Masters in Bioethics from the Katholieke Univesitiet Leuven, Belgium and the PhD degree from the Radboud University Nijmegen in the Netherlands. She is clinical pharmacologist and toxicologist and has a master of public health degree. Her field of work covers areas of medical ethics, bioethics and public health.

Abstract:

Bioethics, society and politics is there a palce for dialogue?

The relationship between bioethics and politics has been present form the very beginning of bioethics. This relationship emerged through discussion of bioethical issues within the society and politics. Since bioethics started as a reflection on the ethical issues raised by the new theologies in health and science. Author Edmund Pellegrino raised the following question regarding relationship between bioethics and politics: „When Ethics does enter the public square can it co –exist with politics or is Machiavelli right that the politics has no place for ethics? This contribution aims to explore relationship between bioethics and politics through several important issues in bioethics based on historical examples drawing parallels regarding past and present situations and development. The issues of expert bioethics committees and deliberative democracy together with term biopolitics will be analyzed. Possible tool for better analysis of the relationship between bioethics and politics based on the analysis of public discourse will presented.



Abstract Book

Parallel Session 3
Room 2TM
Chair: Ralf Jox

(64) Title: Ethics and Governance of Digital Epidemiology: Looking Beyond Privacy

Authors: Agata Ferretti, Postdoctoral Researcher, ETH Zurich

Abstract:
Digital epidemiology showed great potential to collect large volumes of data during the COVID-19 pandemic. Indeed, health data can help monitor epidemics and combat public health threats more effectively. Despite their great potential, these new technologies also bring several ethical and governance challenges. Building upon the COVID-19 pandemic case, we highlight that the issue of individual privacy has dominated the ethical debate of public health surveillance technologies. Although the privacy concern is of utmost importance, this focus has left other important issues and their ethical consequences unaddressed. With this article, we aim to investigate these overlooked issues. Therefore, we explore the problem of the digital divide, the role played by technology companies in public health, and the reuse of personal data, especially in the absence of adequate public involvement. We conclude by arguing that disregarding these issues not only undermines the power and acceptability of health surveillance technology, but also translates into tools that may erode equity, fairness, public trust, equitable distribution of benefits, autonomy, and minimization of group harm. Hence, our call for deeper consideration of these issues, for a broader ethical and data governance approach, and for meaningful public engagement with the goal to foster digital tools adoption and promote public health benefits.

(65) Title: Exploring the ethical issues of digital therapeutics (DTx)

Authors: Refolo P (Adjunct Professor), Sacchini D (Associate Professor), Spagnolo AG (Full Professor), Department of Healtcare Surveillance and Bioethics, Università Cattolica del Sacro Cuore, Rome

Abstract:
Digital therapeutics (DTx) are innovative evidence-based medical interventions, driven by high-quality software programs to prevent, manage, or treat diseases of patients. DTx are also defined as "drugs" where algorithms are the active ingredient instead of a chemical or biological substance. DTX can be used alone or in combination with other devices or medications. DTxs are finding application in a variety of areas, including chronic diseases (type II diabetes, hypertension, obesity, insomnia, Alzheimer's), and above all addictions (alcohol, smoking, and drugs). To date there are roughly 35 to 40 products on the market, 8 of which approved by regulatory agencies. The value of the global DTx market has been estimated at USD 1.8 billion in 2018, and it is expected to reach USD 8.9 billion by 2027. DTx differ from common wellness apps or medication reminder tools in that they require "rigorous" clinical evidence. However, their use raises a number of ethical concerns.
Aim of the present work is to provide an overview of the main ethical issues pertaining the assessment of this emerging technology. The final purpose is to support and facilitate an open and transparent ethical debate with regard to DTx.

(66) Title: Places and time for reflection on data protection in health care

Authors: Elena Loevskaya, IMEW and Dr. Katrin Grüber, IMEW

Abstract:
Background: The increasing digitalisation and use of technology in hospitals and care facilities brings new ethical challenges for caregivers, especially with regard to issues relevant to data protection. Legal aspects are usually in the foreground. However, ethical issues are particularly relevant in everyday care because values such as privacy or (informational) self-determination are at stake here. A structured ethical reflection would therefore be necessary. The question, however, is what possibility there is that goes beyond individual reflection or exchange with colleagues at the workplace and is not delegated to ethics committees. It has to be taken into account that the lack of time of the nurses as a consequence of scarce personnel resources and tightly timed nursing procedures represent a considerable hurdle for a structured ethical reflection.
Method: Within the framework of the PPZ-Berlin project, IMEW conducts literature research and analyses, individual and group interviews as well as participant and non-participant observations.
Results/Theses: Structured ethical reflections have a chance if they are low-threshold and not time-consuming, if they take place as close as possible to everyday care and if concrete references can be made to the diverse questions and tasks of everyday care, for example to the ethical aspects of data protection.
Implication for practice: The presentation will show where and when ethical reflection can take place and how awareness of a comprehensive concept of data protection can be raised in relation to the use of digital technologies.

(67) Title: Inalienable Data: A Challenge to Medical AI's Social Licence

Authors: Francis McKay, Postdoctoral Researcher, The Ethox Centre at the University of Oxford

Abstract:
Many legal and regulatory precedents allow for the sharing of de-identified health data for the training of medical AI systems without obtaining opt-in consent from data subjects beforehand. The ethical grounds for doing so largely stem from the reduced risks to patient privacy that anonymity brings and the limited interests data subjects possess in anonymised data. Yet, as several examples of public backlash over medical data sharing reveal, there are nonetheless persistent concerns from the public regarding de-identified data sharing. In some cases, these collective concerns have frustrated efforts to build efficient medical data sharing systems, and they promise to continue to do so in the future if not addressed.
This paper delves into one key cause for that public reaction: an anthropological phenomenon I call the "inalienability of data." The problem, which I derive from ethnographic research amongst patient and public involvement groups over the past two years, refers to a persistent anthropological imaginary regarding the ownership of health information, in which de-identified data remains symbolically linked back to the original data subject, despite sufficient technological attempts to remove them as a referent. This phenomena, I argue, is widespread, and can shape ethical expectations of patients and the public regarding the rights they ought to have over the sharing of medical data. In many cases, these expectations also go counter to current legal and bioethical licences for de-identified

data sharing, and insofar as they do, provide a challenge to prevailing ethical precedents and to the acquisition of a social licence for medical AI research. Solving that problem is central, then, to the future continuance of medical AI research. I therefore conclude by offering suggestions on what to do in light of that persistent problem.

(68) Title: Czech radiographers' perception of ethical aspects of their profession

Authors: Jiri Simek, (prof. ass., MUDr.), Friedo Zölzer, (prof., dr.rer.nat., DSc.), University of South Bohemia in Ceske Budejovice, Faculty for Health and Social Studies

Abstract:
In the Czech Republic, ethical issues are almost absent in public space. There is no department of ethics at the Czech faculties of philosophy. In contrast, ethics is taught at majority of faculties of medicine and at faculties non-medical medical disciplines. Here is one of the reasons for conducting the study of the perception of ethics by 40 radiographers and 30 radiography students in the Czech Republic.
Most respondents confirmed that they considered the topic to be important for their profession. 60% of radiographers and 67% of students did first hear about ethics at university.
The majority of radiographers, but only few students, had encountered some ethical dilemma during their work. Almost all were aware of the existence of a Code of Ethics for radiographers.
Among the factors which may have a negative influence on their performance as radiographers, respondents named time pressure, high patient throughput, poor relationships among co-workers, and work exhaustion.
A big problem for radiographers is knowing who they can turn to when they encounter ethical dilemmas. In the questionnaires, 47% of the radiographers in Prague felt that they had adequate support at work. 33% indicated that department meetings were the place to address such questions. 37% found personal conversations more helpful.
We have come to the conclusion that ethical education at universities enables Czech radiologists to become more aware of ethical issues when they encounter them. More attention should be paid to the possibilities of resolving ethical dilemmas associated with the radiologist profession.

Parallel Session 3
Room 3TM
Chair: Jan Schildmann

(69) Title: Ethical challenges in policy-making during the COVID-19 pandemic and the use of digital health apps

Authors: Dr. Caroline Brall, Prof. Dr. Rouven Porz, Prof. Dr. Dr. Ralf J. Jox

Abstract:
Background: The Covid-19 pandemic posed and still poses many unprecedented challenges to health care systems and public health efforts worldwide. Policy-making and science were deeply intertwined, in particular with regard to the justification of health policy measures. In this context, ethical considerations were often at the core of decision-making trade-offs. In contrast to the SARS outbreak in 2002, the technological context has significantly changed: Digital health apps for the general public (e.g. the SwissCovid app for contact tracing and the Covid Cert app for showing Covid certificates) were used for the first time in this form during this pandemic in Switzerland and most other European countries.
Aim: The aim of our study is therefore twofold: (1) to explore the ethical challenges during Covid-19-related political decision-making in Switzerland, including the role of ethics counseling; (2) to evaluate the use of digital health apps as part of the health policy response during the Covid-19 pandemic in Switzerland.
Methods: We conducted expert interviews with policy-makers, scientists and other stakeholders involved in decision-making on Covid-19 policy responses in Switzerland on the national level.
Results: The analysis of the interviews revealed that ethical considerations were central during decision-making on Covid-19 policies in Switzerland. Interviewees highlighted a multitude of ethical challenges and expressed which ones were central in their view. Moreover, interviewees estimated that ethics assistance was adequately present in the decision-making process but proposed other methods to foster such ethics assistance in the future, such as ongoing communication channels via Slack or checklists and flow charts on ethics issues. Lastly, interviewees evaluate the use of digital health apps very positively and indicated that the collection and use of health data by digital means could have been extended as part of the pandemic response.
Conclusion: The study can help to develop ethical public health policy advice on pandemic preparedness. Additionally, it provides insights and recommendations from an ethical perspective on the future use of digital health apps and health data as part of pandemic responses and in the field of public health and healthcare in general. Potentially, it can inform health policy-making not only in Switzerland, but also in other countries.

(70) Title: Moral injury among ICU professionals during the COVID-19 pandemic: a prospective qualitative serial interview study

Authors: Niek Kok MSc, Marieke Zegers PhD, Hans van der Hoeven PhD MD, Malaika Fuchs MD, Cornelia Hoedemaekers PhD MD, Jelle van Gurp PhD, Radboud University Medical Center and Canisius Wilhelmina Hospital

Abstract:
Objectives: During the COVID-2019 pandemic, many have stressed that intensive care unit professionals are at risk of developing moral injury. Moral injury is a relatively novel concept in the domain of medicine. There is, however, a rich literature on moral distress. We explored whether, how, and when moral injury develops among ICU professionals in pandemic circumstances.
Design: Prospective qualitative serial interview study with six-month intervals between interviews.
Participants: 59 interviews were conducted with 26 intensive care unit professionals, including intensivists, fellows, residents, and nurses who provided care during the COVID-19 pandemic.
Setting: Six intensive care units of a Dutch university medical center and a separate teaching hospital.
Results: Professionals experienced powerlessness and failure in patient-related situations, and abandonment or betrayal by society, politics, or their employers. For instance, because of societal failure to comply with COVID-19 regulations. Professionals gradually numbed themselves emotionally from patients and/or families as well as potentially impactful events in their work. This simultaneously caused disorientation and/or self-alienation. For example, blaming patients for contracting COVID-19 led to feeling ashamed. For some professionals, organizational, societal, and political responses to the pandemic enhanced numbness and self-alienation. Feelings of betrayal stimulated

processes of displacement of responsibility for morally deplorable outcomes to society and/or politics, for instance: holding patients responsible for not being vaccinated. This helped to suppress feeling personally guilty or ashamed in situations where patients or their families could not be adequately supported.
Conclusions: The findings show that ICU professionals experienced feelings which have previously been described as signs of moral injury. We generally observe that feelings of moral injury are caused by damaged relationships with society and politics and lead to detached relations with patients and/or families and oneself. Feelings of guilt and/or shame, which are commonly seen as indicators of moral injury, appeared less pronounced. Given the timeframe of this study, we cannot be sure that professionals have developed moral injury since they may 'recover' their moral framework, and as a qualification, moral injury should be used lightly. We suggest measures which could help ICU professionals to come to terms with morally injurious experiences.

(71) Title: The Precautionary Principle in the COVID-19 vaccination campaign: the complicated relationship between the scientific community, medicines regulatory agencies and citizens.

Authors: Lobello Paola Aurora (School of Medicine, University of Insubria, Varese and Como, Italy) , Squizzato Alessandro (MD, PhD, Research Center of Thromboembolic Disorders and Antithrombotic Therapies, ASST Lariana, University of Insubria, Como, Italy), Picozzi Mario (MD, PhD, Director, Center for Clinical Ethics, University of Insubria, Varese, Italy)

Abstract:
Coronavirus Disease 19 pandemic and vaccination campaign showed a frail relationship between the scientific community, medical authorities, and citizens. This clearly emerged when unexpected cases of unusual site venous thrombosis with thrombocytopenia occurred (mainly) in young women that received the Vaxzevria vaccine during the first half of March 2021. Suspicion on the possible causal role of vaccine immediately spread in the scientific community and in public opinion, supported by media concerns. As a first step, many European medicines regulatory agencies decided to stop the administration of some batches of Vaxzevria used in patients who developed the new critical syndrome. Few days later, the same authorities opted for a total suspension of the use of the Vaxzevria vaccine; however, the administration restarted in three days, since institutions concluded for the preponderance of vaccine benefits without a significant increased risk of overall thrombotic events, while admitting a possible correlation among mainly unusual site thrombosis and thrombocytopenia. Only in the following weeks several researchers better characterized this rare new vaccine-related syndrome and it was proposed to name it Vaccine-induced Immune Thrombotic Thrombocytopenia.
This work aimed at analysing the way the Precautionary Principle was applied in this situation, and its effects. In fact, the case of the interruption and restart of the vaccination campaign is fully reflected in the application field of the Precautionary Principle; as matter of fact, the thrombotic adverse effects of the vaccine were unknown, their possible causal association with vaccination was uncertain, but they constituted nevertheless a serious and irreversible damage for people's health. Actually, it is impossible to deny that the consequences of the vaccine administration interruption constituted a risk with the same high priority. At the same time, the sudden alternation of opposite decisions by medicines regulatory agencies completely disoriented citizens, to whom concerns about vaccine safety were added to the fear for the pandemic situation. In this context, some interesting considerations emerged on the role of authorities, on the meaning of their action in the decision-making process and on the perspective of responsibility they could embrace in their relationship with citizens.

(72) Title: Crisis and Challenges for bioethics after Covid-19

Authors: Renzo Pegoraro, Professor, Chancellor of the Pontifical Academy for Life

Abstract:
The Covid-19 pandemic took everyone by surprise and, unfortunately, it found everyone seriously unprepared at all levels: health, socio-economics, culture, politics. Even Bioethics has found itself in a difficult position and, I would say, it has been taken by surprise, overwhelmed by urgencies, tragedies, evaluations and difficult decisions to be made, which have tended to leave it silent.
Bioethics as it has developed in recent decades, has found itself "catapulted" in areas rarely frequented, becoming aware of its links with them. Such as: ethics of public health, socio-health emergencies of great magnitude, the organization of health systems, the available resources, the protection of health and other important goods such as work, social relations, and the protection of the most vulnerable. Some more relevant ethical issues that have emerged with the pandemic

(a) The relationship between the personal good and the public good, i.e. the limitations of individual freedom to ensure the control and reduction of the pandemic
(b) Privacy and confidentiality of data
(c) Informed consent for hospitalization
(d) Attention to the frail and elderly
(e) The provision and management of palliative care
(f) The need for justice and equity
(g) Triage for access to the hospital, in particular intensive care units
(h) The issues of health planning and organization, allocation of financial and human resources, the necessary synergistic and coordinated relationship between hospital and territory, the need for adequate and updated "pandemic plans"
(i) Support for all health care workers, helping them to discern between the responsibility of caring for the sick and protecting themselves.
(j) The ethical problems related to the production, distribution and administration of vaccines with confirmed efficacy.

It will be important to develop a bioethics able to better take up and declare fundamental ethical principles such as justice, solidarity, common good, vulnerability, and responsibility. It now seems increasingly urgent to develop a "global bioethics" that includes environmental issues, health indicators, the social and health structures of each country, and the global vision of health and the interconnectedness of peoples (see the work by Henk ten Have).

(73) Title: IS HIV Pre-Exposure Prophylaxis (or PrEP) "Just a pill"? What do users and prescriptors say about it? Results of a qualitative clinical ethics study.

Authors: Nicolas Foureur, Centre d'éthique clinique, Assistance Publique des hôpitaux de Paris

Abstract:
Pre-Exposure Prophylaxis (or PrEP) is a pill and a new tool for HIV prevention. It has been used for a few years, more specifically since 2017 in France. The enthusiasm for PrEP quickly erased the questions, some of them ethical, that preceded its implementation: potential side effects

of the drug, protection from HIV but not from other STIs, risks of sexual disinhibition, etc. While few studies in the world have looked at the ethical stance towards PrEP among users and even fewer among professionals, a study conducted by the Clinical Ethics Center in Paris, between 2017 and 2020, can provide elements for discussion about this method of prevention.

Pairs of doctor/non-doctor researchers (philosopher, lawyer, journalist, caregiver) met for clinical ethics interviews lasting approximately one hour:

- 31 users (30 Men having Sex with Men including 1 asylum seeker, 30% of them consumers of psychoactive substances)
- 21 professionals (15 doctors and 6 PrEP users counselors - from 7 hospitals, 1 LGBT health center and 1 general practice).

On the one hand taking PrEP allows its users to "liberate" their sexuality with respect to the fear of HIV, but on the other hand it does not prevent them from asking questions about their own sexuality, and it can even raise new ones. In this respect, they value peer community support for PrEP, which can contrast with a very personal approach to prevention on their part.

Contrary to these very intimate questions, professionals promote PrEP for medical reasons and collective prevention, and can question their responsibility (are PrEP users' patients?) and the meaning of their profession (am I confined to a role of service provider?).

Based on these results, the presentation will allow us to discuss the contrast between questions that PrEP raises regarding personal sexual fulfillment and the promotion of a certain form of medicalization of sexuality for public health purposes. Moreover, although PrEP is used and prescribed as an "empowerment tool" with regard to sexual health, one can wonder if it still best serves the autonomy of the main concerned people, PrEP users.

Parallel Session 3
Room 4TM
Chair: Emanuele Valenti

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(74) Title: Come Together? Empirical Bioethics and Socio-Legal Studies in Dialogue

Authors: Richard Huxtable, Professor of Medical Ethics and Law, Centre for Ethics in Medicine, University of Bristol, UK

Abstract:

The BABEL project is an interdisciplinary research project based at the University of Bristol, which is kindly funded by the Wellcome Trust. The project explores the ethical and legal dimensions of "best interests" decisions in healthcare, and its approach draws on bioethical, legal and empirical methodologies (and methods). In this presentation, I reflect on the similarities and differences between "empirical bioethics" and "socio-legal studies" and, taking a cue from The Beatles, explore what each may learn from the other when the two come together.

I start with five similarities that empirical bioethics and socio-legal studies appear to share. First, they each have reactive origins i.e. each field emerged as a reaction to perceived problems, which were identified within the originating fields or disciplines (law and bioethics, respectively) and also from without. Second, each looks to the social sciences for help in addressing the perceived problems. Third, they share similar aims to address ethical concerns and to change things in practice. Fourth, they each seek to meet those aims through interdisciplinary work, which involves integrating the social sciences with the originating fields. Such work brings challenges (e.g. around publication and assessment), but is also supported and encouraged by those that fund and support research. Fifth, each is pluralistic in nature, rejecting traditional disciplinary boundaries and encompassing a broad range of approaches.

Such pluralism is celebrated in both fields, as it allows for rich creativity. The various similarities between empirical bioethics and socio-legal studies suggest that bringing them into dialogue could present opportunities. The two endeavours certainly have some shared interests and approaches. However, they also make distinctive contributions, from which the other might learn: for example, socio-legal studies is more overtly directed towards law and policy and has a longer history of engagement with the social sciences, while empirical bioethics has focused on integrating theoretical and empirical findings, reaching normative conclusions, and developing standards of practice. To illustrate the opportunities for creativity and sharing learning, I will close by outlining how the BABEL project is seeking to learn from – and bring together – the two fields.

(75) Title: Legal but unethical? Persuasion or coercion? Showing how and why ethical analysis is vital in a pandemic

Authors: Alex McKeown, PhD - Department of Psychiatry / Wellcome Centre for Ethics and Humanities / UK Pandemic Ethics Accelerator, University of Oxford

Abstract:

We present a case showing how bioethical expertise can be brought to bear on dilemmas at the intersection of ethics and law in Covid-19 and other pandemics, focusing on the ambiguous boundary between persuasion and coercion in efforts to increase vaccination among less-vaccinated communities. We tie this analysis to general ethical debate about circumstances in which it is legitimate to refuse health advice, drawing on work by Jonas (2016; 2017). Our analysis delivers valuable reflections about the role of bioethics in national political decisions; justice, solidarity, equity in healthcare; and rethinking the role of bioethics after Covid-19.

The UK Pandemic Ethics Accelerator was approached by a data governance consultancy to advise on ethical ramifications of a scheme about which they were providing legal advice for a client. In the scheme, NHS Trusts would provide information about vaccination status of individuals to local authorities, so these individuals could be contacted directly, by telephone or door-to-door, with the explicit aim of increasing vaccine uptake. Although the scheme would be legal in the UK, importantly, it would not necessarily be ethically permissible.

The scheme assumes individuals should agree to vaccination because it would be better both for them and for others. Thus, a subordinate intended benefit is that individuals come to acquire accurate knowledge about Covid-19 vaccination, so they can decide in full possession of all relevant information. However, this would require integrating unbiased information into a scheme which overtly defines success by increased vaccination rates, and in which better-informed refusal counts as failure. This is challenging. It is unclear that any communication involved can be non-directive as claimed, given that the scheme aims at one particular outcome. Additionally, the scheme would be carried out by people in positions of authority and power, relative to the individuals targeted, further undermining the advice's apparent neutrality. For these reasons and others to be presented, attention must be paid to the risk that the scheme is perniciously coercive.

We use Jonas' work on conditions for legitimately refusing health advice to frame the analysis, making recommendations for how bioethics might help manage similar situations in future pandemics.

(76) Title: The role of common sense in bioethical decisions: prefiguring unpredictable outcomes and side effects

Authors: Elvira Passaro, Doctoral researcher at Medicina Clinica e Sperimentale e Medical Humanities - University of Insubria and Céline Pieters, Postdoctoral researcher at Philosophy and Media of Technology - University of Vienna

Abstract:
Going from Aristotle to Chaïm Perelman and through Giambattista Vico, we support the idea that the principle of phronesis (practical wisdom) cannot be avoided when trying to deal with ethical questions that need to lead to a decision. More precisely, we argue that phronesis is regulated by the common sense which is necessary in cases where a decision has to be made without knowing and being able to anticipate every possible outcome and side effect. For instance, it is the case of decisions that follow a deliberation in the context of medical ethics (moral conflict with patients, life choice, resources allocation, etc.). It is also the case in the making of the regulations, ethical guidelines or policy manuals. As Miguel Benasayag reminds us, "we must understand, accepting a minimum of complexity, that the conscious objective of an act cannot encompass the full range of foreseeable or desirable consequences triggered by that act".
In these situations, and despite the fact that it would certainly be more comfortable to consider every action as being linear (cause-and-effect articulation), we argue that a deductive reasoning cannot help to prefigure all future scenarios. In other words, unlike in the rationalistic tradition, it is here about being inventive rather than strictly logical (which excludes anything changeable and arbitrary). In that case, imagination allows us to figure and experiment with knowledge that cannot be accessed otherwise. By working with transformation, connection, separation and composition, the faculty to imagine (Vico) is the one that enables to create a bond between actual data and unpredictable effects.
In this paper, we firstly describe how the principle of phronesis is regulated by common sense and how this latter suits decisions where all consequences cannot be planned. We also show how common sense is guided by imagination. In the second part, we discuss these notions through a case study in the field of bioethics.

(77) Title: The application of best interests standard in healthcare: a narrative synthesis of empirical studies

Authors: Emanuele Valenti, Richard Huxtable, Centre for Ethics in Medicine, University of Bristol, UK

Abstract:
The best interests standard is used to make decisions involving people who lack capacity and cannot express their wishes about treatment. Although the standard features in the legal frameworks and policies of such countries as the United Kingdom, the United States, Australia, and Canada, its meaning is contested. In ethical theory, conceptualisations of best interests are vague or ambiguous, while, in healthcare practice, professionals, patients, careers and advocates differ in their understandings of what is in a patient's "best interests".
The BABEL project, based at the University of Bristol and funded by the Wellcome Trust, explores "best interests" decisions in England and Wales for patients across the life course. Seeking also to learn from elsewhere, this presentation outlines the findings of a systematic search of the literature, which seeks to synthesise existing empirical evidence concerning the application of the best interests standard in healthcare internationally. A multi-disciplinary team carried out a narrative synthesis of international qualitative studies. Between April 2019 and December 2020, a systematic search of electronic databases, Medline and Web of Science identified 52 studies, which were thematically analysed and synthesised.
We developed three main themes: 1) how best interests decisions are reached between healthcare professionals, patients and relatives; 2) the broad bases on which best interests decisions are made; and 3) the narrower basis on which best interests decisions are made. The first theme depicts how and why communication between professionals and patients is an important ongoing process. The second theme captures the broad basis on which decisions are made, in which different bases seem to be used, some focusing on the patient's wishes, others concentrating on what the patient needs. The former basis is voiced by family and relatives and corresponds with ethical notions like respect for autonomy and substituted judgement, while the latter basis tends to be offered by health care professionals. The third theme captures the factors influencing the decisions that are made, including notions of autonomy, benefit and harm. The review is part of a research project in medical ethics and law led by Prof. Richard Huxtable at the Centre for Ethics in Medicine, University of Bristol, funded by Wellcome Trust.

Parallel Session 3
Room 7TM
Chair: Chris Gastmans

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(78) Title: Understanding the impact of artificial intelligence (AI) on physician-patient relationship models

Authors: Francesca Greco, PhD student, Department of Biotechnology and Science of Life, Center for Clinical Ethics, University of Insubria (Varese, IT); Mario Picozzi, Director of the Center for Clinical Ethics, Biotechnology and Science of Life Department, University of Insubria (Varese, IT).

Abstract:
The physician-patient relationship has undergone a transition throughout the ages. The introduction of Artificial Intelligence (AI) in recent years, however, is redefining this relationship. The four main relationship models described by Emanuel & Emanuel in 1992 are called paternalistic, informative, interpretive, and deliberative. The aim of this study is to understand how classic models of doctor-patient relationships are changing when considering the impact AI has on everyday medical practice.
In the paternalistic model, physicians decide which treatment is best and patients put decision-making responsibility in the hands of the physician. The introduction of AI strengthens the physician's role, resulting in the so-called digital paternalism.
In the informative model, the physicians provide information about treatment options, but patients have the last decision. Here AI may put the patient in an unfavorable position by not being able to fully understand this degree of medical information and inducing him to follow medical advice without any discussion. Also, the patient might believe that the provided treatment options are given directly by AI, so the physician's role loses its relevance.
In the interpretive model, physicians act as a consultant, assisting patients in the choice of treatment. As in the informative model, it is necessary to define the source of the information presented to the patient.
In the deliberative model, the physician engages the patient in a dialogue on treatment choices implying a continuous exchange of information. AI could increase the patient's trust in the doctor by knowing that various therapeutic choices are being discussed and fully explained.

It's complicated to understand whether the trust relationship established between doctor and patient remains bi-univocal, by incorporating AI in the clinician's figure, or whether AI must be introduced as a separate entity implying an asymmetry in this relationship. An effort in communication is fundamentally important since every choice dictated by AI must be explained to the patient so as not to fall into digital paternalism. It is relevant to educate doctors on the new models of relationships that can be created, in addition to studying patient populations within the context of these models' framework.

(79) Title: A matter of uncertainty – Patient's perspective on the challenges of AI-based clinical decision support systems

Authors: Dr. Wenke Liedtke, Protestant University of Applied Sciences, Bochum, Germany, Diana Schneider, Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe, Germany, Andrea Klausen, Institute of Medical Informatics, Uniklinik RWTH Aachen, Aachen, Germany, Dr. Nils Heyen Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe, Germany, Dr. Tanja Bratan, Fraunhofer Institute for Systems and Innovation Research ISI, Karlsruhe, Germany, Prof. Dr. Martin Langanke, Protestant University of Applied Sciences, Bochum, Germany

Abstract:
AI-based clinical decision support systems (CDSS) are becoming increasingly important in routine and emergency healthcare due to their predictive capabilities and potential to enhance efficiency of workflows. This talk addresses patients' perspectives on the potential use of AI-based CDSS and the corresponding responsibility-related issues. Thereby it focusses on challenges of the dialogue between patients and health care professionals in digital healthcare.
Based on qualitative data from focus groups investigating the impact of AI-based CDSS and conducted as part of the German Ministry of Education and Research funded consortium DESIREE ("Decision Support in Routine and Emergency Health Care: Ethical and Social Implications"), this presentation highlights three thematic clusters raised by patients related to the transformation of medical care through AI-based CDSS: Firstly, patients articulate a dilemma regarding the trustworthiness of diagnosis and therapy recommendations generated by technical systems relative to those generated by healthcare professionals. Secondly, patients see potential implications for their conception of the healthcare professionals' roles. Is the clinician of the future merely a handler of a technological decision support system and who will ultimately be responsible for medical decisions? The final set of topics deals with the patients' own roles and how they might change. Are they facing a new personal responsibility? How can informed consent for the use of such systems be meaningfully acquired? Should they be informed in advance about the extent of the use of such systems?
The presentation will reflect on these three aspects from an ethical perspective using a relational approach to responsibility. Moreover, it will address the issue of a possible regulatory desideratum by the European Medical Devices Regulation about patients' articulated uncertainties and, if applicable, identify needs for specification where possible application scenarios of AI-based CDSS do not fit the established category system of the Medical Devices Regulation.

(80) Title: Inclusion or experimentation: the role of ethics committees in the entry of AI into clinical practice

Authors: Marisei M., MD, Casella C., PhD, Dei Medici S., MD, Policino F., MD, PhD, Di Lorenzo P., MD Associate Professor , Capasso E. MD, PhD, Niola M. Full Professor- Dep. of Advanced Biomedical Science- Legal Medicine- University Federico II- Naples

Abstract:
The inclusion of AI for supplementary or replacement purposes in some production activities and in certain sectors, has serious social repercussions.
Ethics stands as a bulwark of any indiscriminate introduction or total takeover of the mechanical component at the level of crucial sectors, such as Healthcare.
Intelligent machines, if we want to define them in this way, would be configured as computers and processors of aggregate data capable of returning useful information for the satisfaction of clinical, laboratory or instrumental criteria to make a diagnosis or to support and address the therapeutic strategy.
In this regard, the ethics committees are vital in assessing the appropriateness of introducing such IT aids within clinical practice
In the experimentation phase, it seems appropriate that initiatives aimed at testing the appropriateness of the introduction of artificial intelligence tools (attributable to one or more of the three constitutive pillars of artificial intelligence, namely algorithms, network of things and data) should be considered as clinical trial projects and must therefore undergo analysis and expression of ethical opinion by local ethics committees.
In the no less delicate phase, however, of extending the use of a tool belonging to the world of artificial intelligence, the scrutiny of a single committee for "roboetics" appears very necessary.
Returning to the antinomic inclusion / experimentation, it seems appropriate to define first of all that these are two moments that arise in temporal continuity, where experimentation is a prelude to inclusive use.

(81) Title: Levels of explicability for medical artificial intelligence: What do we need and what can we get?

Authors: Dr. Frank Ursin (Postdoc, Institute for Ethics, History and Philosophy of Medicine, Hannover Medical School (MHH), Hannover, Germany), Prof. Felix Lindner (Institute for Artificial Intelligence, Ulm University, Ulm, Germany), Prof. Timo Ropinski (Visual Computing Group, Ulm University, Ulm, Germany), Prof. Dr. Dr. Sabine Salloch (Institute for Ethics, History and Philosophy of Medicine, Hannover Medical School (MHH), Hannover, Germany), Dr. Cristian Timmermann (Ethics of Medicine, Medical Faculty, University of Augsburg, Augsburg, Germany)

Abstract:
The umbrella term explicability refers to efforts to reduce the opacity of artificial intelligence (AI) systems. These efforts are considered crucial for diagnostic AI applications because there are tradeoffs between accuracy and opacity. This entails ethical tensions because it is desired by doctors and patients to trace how results are produced while improving performance without ethical compromises. The centrality of explicability invites to reflect on the ethical requirements for diagnostic AI systems. These requirements originate from the fiduciary doctor-patient-relationship and contain aspects of informed consent. Therefore, we address the question: "What level of explicability is needed to properly obtain informed consent when utilizing AI?" The aim of this work is to determine the levels of explicability required for ethically

defensible informed consent processes and how they can technically be met by developers of medical AI.
We proceed in four steps: First, we define the terms commonly associated with explicability as described in the literature, i.e. explainability, interpretability, understandability, comprehensibility, demonstrability, and transparency. Second, to place these results in context, we conduct a conceptual analysis of the ethical requirements for explicability when it comes to informed consent. The framework consists of the five elements of informed consent: information disclosure, understanding, voluntariness, competence, and the decision. Third, each of these aspects is examined in relation to the different components of explicability identified in the first step. These results allow to conclude which level of explicability physicians must provide and what patients can expect. In a last step, we survey whether and how the identified levels of explicability can technically be met from the perspective of computer science. To this end, we discuss recent attempts of developing explainable AI. Throughout our work, we take diagnostic systems in radiology as an example, because AI aided diagnostic systems are already commercially available and are clinically applied in this specialty.

(82) Title: On realizing interdisciplinary research to develop equity promoting AI in health

Authors: Hallvard Fossheim (corr.) & Kristine Baeroe

Abstract:
There are a number of ethical challenges associated with Artificial Intelligence (AI) in health. Among them are issues of balancing openness and privacy protection; the proliferation of discriminatory biases; challenges that concern algorithm transparency; and issues of responsibility in AI based decision-making.
Research aimed at addressing global societal challenges in health is deeply embedded in challenges related to poverty and inequality in the distribution of power and social benefits. Helpful answers must address not only what ethics and justice in principle entail in health, but also relate to the social dimension of power that surrounds normative decisions: Who should decide, how, and when?
Against this background, we are facing new, urgent ethico-political challenges related to developing, deploying, and using AI to improve health equity. These challenges relate to a crucial scientific and epistemic question: How can we realize truly interdisciplinary collaboration among researchers from medicine, law, economics, social sciences, and AI developers in the development of new, ethical and health promoting technology?
In this presentation, we will focus on ongoing work on identifying enablers and obstacles to realizing interdisciplinary research to develop equity promoting AI solutions in health.
AI oriented research in health has to an important degree been not only multidisciplinary, but also interdisciplinary. This creates new opportunities and insights, but also real challenges. We are in the process of refining a set of experience-based rules and principles that can serve as a help in coordinating processes towards valuable insights while avoiding some of the pitfalls. The methodology is necessarily complex; three basic points of departure concern
- Cognitive coordination of concept development;
- Constructively Socratic attitude;
- Cross-disciplinary processes of production.

Since the process is still ongoing and our approach is experience-based, we will treat our session as both a presenting of results and as an occasion for input aimed at the further refinement and development of those results.

Parallel Session 3
Room 8TM
Chair: Pascal Borry

(83) Title: Incidental Findings Disclosure in the Context of Genetic Research: The Understanding and Approaches

Authors: Saleh AlGhamdi , PhD , KFMC - Isamme AlFayyad , MSc , KFMC - Mohamad Al-Tannir MppA, KFMC

Abstract:
Background: Clinical genomic professionals are increasingly facing decisions about returning incidental findings (IFs) from genetic research. Although previous studies have shown that research participants are interested in receiving IFs, yet there has been an argument about the extent of researchers' obligation to return IFs. The Aim of this study was to explore the perspectives of clinical genomics professionals toward returning incidental findings from genomic research.
Methods: A national survey was conducted and included a sample (n = 113) of clinical genomic professionals using a convenient sampling. A self-administered questionnaire was used to explore their attitudes toward disclosure of IFs, their perception of the duties to return IFs and identifying the barriers for disclosure of IFs. A descriptive analysis was employed and used percentages and frequencies.
Results: Sixty-five (57.5%) respondents had faced IFs in their practice and 31 (27.4%) were not comfortable discussing IFs with their research subjects. Less than one-third 34 (30.1%) of the respondents reported the availability of guidelines governing IFs. The majority 84 (80%) and 69 (62.7%) of the study participants indicated they would return the IFs if the Likelihood of disease threat ≥50% and 6-49%, respectively and 36 (31.9%) reported they have no obligation to return IFs.
Conclusion: clinical genomics professionals have positive attitudes and perceptions toward the returning IFs from genomic research, yet some revealed no duty to do so. Detailed guidelines must be established to provide insights into how genomics professionals should handle IFs.
Keywords: incidental findings; disclosure, genomic research, attitudes, perception, barriers, Saudi Arabia

(84) Title: Ethical issues of the secondary use of genetic data in research

Authors: Esquerda Montse, Lorenzo D, Garriga M, Bofarull M

Abstract:
The secondary use of data is defined as "the processing of –rare diseases patients/families– (personal, clinical, and genomic) data by users for different purposes to those that were originally pursued, including research, healthcare and policy development". this reuse has different ethical implications in reference to the field of genetics.
This study presents the result of a project carried out by a research team at the Institut Borja de Bioètica, and it is based on a critical review and discussion of recent medical and scientific literature on the topic, published in the last years.
Different groups of ethical conflicts are identified, for which it is necessary to give them a different response. One of the main ethical problems is related to consent, due to the difficulties of specific consent and the ethical challenges that broad consent represents. The broad consent. The extended consent must guarantee in an exquisite way that the individual understands and accepts the conditions for the reuse of their genetic data, as well as guaranteeing anonymity, confidentiality, the need to carry out the research and the possibility of revocation of consent.

Data protection constitutes one of the ethical conflicts, and as the WHO points out "if possible, personal data should be aggregated or anonymized at source and be kept separate, ideally in physically separated IT systems". Although they are anonymized, these data must have control measures by the biobank before their external sharing. it is important to establish different levels of risk in these data: Some genomic data can clearly identify an individual, but others cannot.
Another of the conflicts would be related to the existence or not in the genetic data of a genetic exceptionalism, that is, if the genetic data present fundamental differences for its safeguarding in relation to other types of data.
Another group of conflicts would be related to the information and communication or re-contact in case of incidental or secondary findings, both to the individual or to the family.

(85) Title: Geneticists and ethicists - a fruitful relationship? Exploring the limits of shared knowledge in common discussions

Authors: Cand. Dr. med. Sabine Hauser and Prof. Dr. Rouven Porz, Medical Ethics Unit, Bern University Hospital, Medical Faculty Bern, Switzerland

Abstract:
For more than 20 years, ethical issues surrounding and relating to the rapidly developing field of genetics have been a hot topic in international bioethics. Genetics itself, genetic testing and the technical possibilities associated with genetic engineering are topics that are strongly based on scientific knowledge and these topics are in constant flux and revision. As clinical ethicists, for example, in our work with members of Reproductive Medicine and Genetics, we often notice a large discrepancy between the scientific knowledge of the genetic specialists and the scientific laypersons (which are often ethicists, lawyers, management staff and so on).
We have therefore developed a small research project that we would like to present. In this project, we ask ourselves the two interrelated questions: (1) what are the basic principles that every lay person needs to understand today in order to be able to understand the opportunities and dangers of the rapid development of genetics? And - now vice versa – (2) what are the basic principles of ethics that every geneticist/scientist needs to understand in order to be able to think along the ethical discourse on his or her field?
The implementation idea of this research project is to culminate in teaching units in order to make the discussion between natural scientists and scientific laypersons more connectable. We would like to present the first results and put them up for discussion.

(86) Title: Discussing genetic enhancement from the perspective of a developing country

Authors: Vorathep Sachdev, PhD Candidate, University of Edinburgh, The Royal (Dick) School of Veterinary Studies

Abstract:
The genetic enhancement debate is an on-going and important one that impacts policies worldwide. Proponents of enhancement envision a world with greater intelligence and well-being, while those in opposition fear the consequences, primarily within Western liberal democracies. Despite the globalized impact of these enhancements, the developing country's perspective is yet to be thoroughly considered. Accordingly, this paper analyzes the diffusion and application of these neoliberal technologies in developing countries and the potential unintended consequences that may occur. Using literature review and comparative analysis from the application of similar past technologies, this paper explores the application of and impact of such technologies in developing countries through a case study of Thailand. The speed at which such genetic enhancement technologies are diffused globally is recognized as a key factor towards what the consequences of these technologies may be in a developing country. The likely slow diffusion of cognitive enhancements to developing countries presents us with at least two main conclusions. First, that the spread of genetic enhancement technologies are inherently neoliberal and colonial in nature, thereby widening the wealth gap between developed and developing countries. For example, patents that shall protect such enhancements shall make them expensive, or create black or gray markets. Second, such enhancements shall create reinforce inequalities created by colonialism and create additional inequalities in these countries. For instance, an authoritarian developing country, may only provide access to such enhancements to the elite. As a result of such research, this paper shall show the inherently neoliberal nature of such genetic enhancements and explore how such technologies may be used when localized into a developing country like Thailand. In essence, this paper hopes to use enhancement technologies as a tool to highlight what the current is lacking and steer the debate to become more inclusive in ethical and policy discussions worldwide.

(87) Title: Instrumentalizing the savior baby? A Belgian case.

Authors: Prof. dr. Adelheid Rigo, docente Vrije Universiteit Brussel, Pleinlaan 2, 1050 Brussels, Belgium & lecturer Odisee, Campus Schaarbeek, Brussels, Belgium; Prof.dr. Johan Stuy, professor Ethics Vrije Universiteit Brussel, Belgium

Abstract:
A Spanish couple with a child suffering from Beta Thalassemia, only curable by bone marrow transplantation, consulted the Brussels University Hospital for a Preimplantation Genetic Testing with HLA Typing. The hospital implanted by mistake a healthy but not HLA-compatible pre-embryo, resulting in the birth of a not-HLA-compatible twin. The parents finally get the healthy and compatible pre-embryo implanted in Madrid and found their 4th child fit as a bone marrow donor. The parents filed a lawsuit in the Belgian tribunal of first instance. Remarkable is the material damage attributed by the judge (2021) for 'a wrong crossing of the family planning' and for 'the impoverishment resulting from the presence of a fourth child' in the family. For the court it was proven that the parents wanted 2 or 3 children but not 4.
The Belgian law stipulates an important condition for allowing parents to make use of PGT/HLA: the wish to have children may not be motivated solely by the therapeutic interest of the other child. Or in Kantian terms the savior baby is not to be valued merely as a means to the ends of others ..., but as an end in himself.
If the parents didn't want a 4th child as part of their parenting project, the conclusion could be that they conceived this child consciously for his genetic traits, as merely a means to save their sick child? Does the court recognize by awarding this material compensation that an instrumentalization of the savor baby is justified?
In previous research we focused how to discover instrumentalization of the future savior baby. We analyzed semi-structured, in-depth interviews of 28 parents asking for PGT/HLA as part of a research project. Parents were among others asked: Would the parents wish a new baby when their sick child wasn't in need of the saviour baby's stem cells? and would parents when a mistake is made and discovered during the pregnancy choose an abortion for a healthy but non-HLA- compatible fetus?
The degree of the intention by the parents to instrumentalize the future savior baby in our research was very low.

Parallel Session 3
Room 9TM
Chair: Federico Nicoli

(88) Title: Animal ethics and organ xenotransplantation: Old problems and new challenges posed by the use of non-human animals in research

Authors: Silvia Ceruti, PhD Student, Department of Biotechnology and Science of Life, Center for Clinical Ethics, University of Insubria, Varese, IT; Giuliano Grignaschi, Head of Animal Welfare, Research Services Division, University of Milan, Milan, IT; Mario Picozzi, Director of the Center for Clinical Ethics, Biotechnology and Life Sciences Department, University of Insubria, Varese, IT

Abstract:
Following the first animal-to-human heart transplant earlier this year in the US, further debate on organ xenotransplantation has been stimulated in the scientific community and the general public, and its implementation is often presented as a possible solution to the problem of the shortage of transplantable human organs.
However, in Italy, a law - currently on pause for three years - banning the use of non-human animals in organ xenotransplantation research is in place. Although the ban itself is currently the subject of an infringement procedure by the EU against Italy, as it does not comply with Directive 2010/63/EU on the protection of animals used for scientific purposes, these restrictions continue to pose serious problems for the future of biomedical research in Italy and make it difficult for Italian scientists to start or participate in research in this field with other European researchers.
In this scenario, the present (still ongoing) project aims to investigate the main ethical issues associated with research involving non-human animals in the field of organ xenotransplantation, to establish whether it can be considered ethically justifiable and, if so, whether - and to what extent - special restrictions should be introduced (or maintained) at national and international level. Specifically, the current analysis concerns ethical issues the social impact of which may be of particular interest not only to the scientific community but also to the general public. These include a) the use of cognitively highly developed non-human animals (e.g. pigs and non-human primates) in research that aims to treat human diseases largely linked to unhealthy lifestyles (e.g. smoking and cardiovascular diseases); b) the use of non-human animals considering the current low percentage of human subjects available for organ donation.
In order to comprehensively analyse these issues, besides conducting a thorough literature review on the topic, the authors opened a call through the European Animal Research Association (EARA) network to connect with researchers across the EU, to collect information on the actual use of non-human animals in organ xenotransplantation research at European level, and to create a network open to all stakeholders to discuss the ethical issues presented.

(89) Title: Ethics of early phase clinical trials of bio-engineered organs: points to consider

Authors: Dide de Jongh, MSc, Department of Medical Ethics, Philosophy and History of Medicine and the Department of Nephrology and Transplantation, Erasmus MC, University Medical Centre Rotterdam, The Netherlands. dr. Emma K. Massey, PhD, Department of Nephrology and Transplantation, Erasmus MC, University Medical Centre Rotterdam, The Netherlands. dr. Eline M. Bunnik, PhD, Department of Medical Ethics, Philosophy and History of Medicine, Erasmus MC, University Medical Centre Rotterdam, The Netherlands.

Abstract:
Regenerative medicine has emerged as a potential response to the persistent problem of shortage of donor organs in the field of organ transplantation. Using technologies such as tissue engineering, and 3D bioprinting, regenerative medicine aims to (re)generate, repair or replace damaged tissues and organs. Around the world, in preclinical research settings, bioartificial organs are being developed that can be used for transplantation into human recipients. Within a couple of years, first-in-humans and early-phase clinical trials are expected to be launched to test the safety and efficacy of these products in patients. In early-phase bio-artificial organ transplantation trials, however, research participants will be exposed to serious risks. As of yet, there is no ethical guidance for the safe and responsible design and conduct of early-phase clinical trials of bioartificial organs. Therefore, research groups and research ethics review committees must look to adjacent fields of research, including regenerative medicine, 3D bioprinting and cell-based therapy, for guidance. In this presentation, we will present the results of a systematic literature review in adjacent fields of research where we have examined relevant ethical points to consider for early-phase clinical trials of transplantable bioartificial organs. 92 scientific peer-reviewed articles were included. Six themes were identified related to: cell source, risk-benefit assessment, patient selection, trial design, informed consent, and oversight. Overall, this review reveals that further ethical empirical research is needed, notably on patient perspectives, to help ensure the development of ethically responsible approaches to patient selection, trial design, and informed consent in early-phase clinical trials.

(90) Title: Simple decision, right? Which reasons influence the decision of researchers for animal experiments and alternatives to animal experiments?

Authors: Ines Pietschmann, PhD student (main presenter), Department for Medical Ethics and History of Medicine, Goettingen University Medical Center; Dr. Hannes Kahrass, Postdoc , Institute of Ethics, History and Philosophy of Medicine, Hannover Medical School; Dr. Marcel Mertz, Postdoc, Institute of Ethics, History and Philosophy of Medicine, Hannover Medical School

Abstract:
Background: Animal experimentation is still an essential, albeit socially controversial part of biomedical research today. The use of animals for ultimately human scientific and health interests is surrounded by critical questions about animal welfare and social value of research. Given these ethical issues, the search for and application of alternatives to animal experiments thus receives great attention from the public and from the biomedical research community itself. However, even though hardly anyone is against alternatives in general, there is considerable debate on the question of whether they are possible everywhere or lead to comparable results. How researchers actually decide in the face of such debates, which reasons they deem decisive to choose between an animal model and a possible alternative (or its development), is therefore of particular interest.
Methods: A qualitative interview study about the choice between animal experiments and alternatives was conducted that included 13 researchers working in basic or translational research. The data was analyzed regarding the reasons mentioned and their underlying value judgments.
Results: In basic and translational research, choosing the method is a complex process because there are a variety of (conflicting) values and pragmatic reasons. A variety of reasons can play a role, mostly related to scientific validity and, in lesser terms, animal welfare, but also to practical considerations such as available infrastructure, research funding, or personal attitudes.

Discussion: In order to be able to make ethically reflected decision, researchers must be aware of the reasons that influence their decision and challenge them. Here it is important to identify which reasons are justified and which are not, and to be aware that underlying fundamental assumptions can change. We propose a reflection/decision aid that can help identifying and evaluating these various reasons.
Conclusion: An open and honest discussion about reasons that play a role in the choice of animal experiments and alternatives can lead to a more constructive discussion within research communities and the public. Within academia, initiatives that improve the somewhat frozen discourse between animal ethics and research ethics seem welcome.

(91) Title: Dialogue in Organ and Tissue Donor Conversations in an Active Donor Registration System

Authors: Sanne van Oosterhout MSc, PhD student, Radboud Institute for Health Sciences, Department of IQ healthcare, Radboud university medical center; dr. Anneke van der Niet, Department of IQ healthcare, Radboud university medical center; Prof. dr. Marianne Boenink, Department of IQ healthcare, Radboud university medical center; dr. Jelle van Gurp, Department of IQ healthcare, Radboud university medical center; dr. Gert Olthuis, Department of IQ healthcare, Radboud university medical center

Abstract:
In the Netherlands, the opt-in donor system has been substituted by a soft opt-out system in 2020. This means that when not actively registered, consent for donation is presumed and relatives should only be informed about donation instead of giving consent. To guarantee a position for relatives, a guideline for doctors has been implemented: The Quality Standard Donation. However, relatives are approached to confirm the default of donation and have some – rather limited – possibilities to object. Therefore, it is expected that the system change has consequences for the dialogue between healthcare professionals and relatives in donor conversations.
Based on existing literature about medical dialogue and our qualitative empirical work, we will present findings and reflections on how healthcare professionals and relatives discuss organ and tissue donation in the new opt-out system. In a multiple case study, we analysed audio-recordings and direct observations of 20 donor conversations (inclusion still ongoing), and supplementary in-depth interviews of intensivists, intensive care nurses and relatives, following a content analysis. Inclusion of eight donor conversations in the opt-in system allows comparing clinical practice before and after the system change.
In our presentation, we will discuss the normative assumptions about donor dialogues underlying the opt-out system and contrast this with empirical insights from clinical cases and the literature. In the latter, a good medical dialogue has been characterised as a dynamic, open, impartial and power neutral conversation focused on mutual understanding and obtaining consensus through deliberation and negotiation. Given the timing of donor dialogues – when relatives experience a life-event and may have limited ability to retain procedural information –, we question whether a dialogue as such is possible. Up to this point, we are inclined to think that ethical implications of the opt-out system are significant, since it can affect the openness and explorative character of donor dialogues and can amplify inequalities between healthcare professionals and relatives. We argue that our data-driven findings are pivotal for understanding and further guiding clinical practice. We want to discuss whether using the concept of dialogue might be misleading in opt-out donation practices and whether an alternative characterisation should be sought.

(92) Title: Exploring the concerns and practices associated with organ transplantation in the context of Muslims in Pakistan from an anthropological perspective.

Authors: Qurratulain Nasiruddin Faheem, PhD. Researcher (3rd year), The University of Sussex

Abstract:
The human body often serves as a reference point to analyse the notions of self and society. Situating on Merleau-Ponty and Bourdieu theories of embodiment, this research explores the notions around the human body and its influence on the ethical considerations in regards to organ transplantation among the Muslim communities in Pakistan. The context of Pakistan makes an intriguing case study as cadaveric organ transplantation is not in practise. Whereas, living organ transplantation is commonly is practised between family members only. These contradictory practices apparently rests on the ideologies around the human body and religious beliefs as well personal judgements and authority of healthcare professionals.
This research is a year-long ethnographic study carried out as part of doctoral studies. An anthropological approach towards organ transplantation in Pakistan brought forward various socio-cultural notions around the human body and selfhood that serve as framework around biomedical ethical issues in various societies. Further, it surface the contradictions and issues associated with organ transplantation that makes it a dilemma situated in a nexus of various socio-cultural and political factors rather seeing it as an isolated health concern. The research bring forward the experiences and stories of organ receivers, organ donors, religious leaders, healthcare professionals and general public which aspire to encourage biomedical ethicists and social-scientists to consider ethnography as a research methodology and rely upon people's lived experiences while establishing policies and practices around biomedical ethical issues.

Parallel Session 3
Room 1PM
Chair: Lucia Galvagni

(93) Title: The influence of Symptom Checker Apps on the patient-physician relationship. Results of a qualitative interview study and ethical analysis

Authors: Regina Müller, M.A. (University Tübingen), Malte Klemmt, M.A. (HAW Würzburg-Schweinfurt), Anna-Jasmin Wetzel, M.Sc. (University Hospital Tübingen), Christine Preiser, M.A., (University Hospital Tübingen), Dr. Roland Koch (University Hospital Tübingen), Marie-Theres Steffen (University Hospital Tübingen), Prof. Hans-Jörg Ehni (University Tübingen), Prof. Tanja Henking (HAW Würzburg-Schweinfurt), Prof. Robert Ranisch (University Potsdam)

Abstract:
Background: Symptom Checker Apps (SCA) are mobile applications for end-users that suggest possible causes for symptoms entered by the user and, based on this, provide recommendations for further action, such as seeking medical advice. SCA enter the previous two-sided relationship between users or patients and physicians and might lead to changes in this relationship, for example, regarding decision-making processes. Using SCA as an example, we analyse in the BMBF-funded joint project "CHECK.APP" how the role of health apps is perceived by their users in connection or in comparison with visits to the physician.
Method: A qualitative interview study was conducted to collect the perspectives of the users. Currently, n=15 SCA users were interviewed.

Semi-structured qualitative interviews were conducted in interviewer tandems with different professional backgrounds. The interview study provides deep insights into the subjective perceptions of SCA and enables the reflected collection of experiences, values and concepts. The integrative basic procedure developed by Kruse is used to analyse and interpret the interviews.
Results (preliminary): The interviewees' experiences refer, among other aspects, to the role of SCA in relation to visits to physicians and the patient-physician relationship, differences to medical consultations or diagnoses, and possible risks concerning the symptom analysis and recommendations of SCA. How the users experience the app's influence on their patient-physician relationship is heterogeneously perceived and sometimes described in contradictory ways within one interview.
Conclusion (preliminary): The study results can contribute to a better understanding of the impact of digital technologies such as SCA on the patient-physician relationship and thus facilitate a responsible introduction of SCA into clinical practice.

(94) Title: Empowerment through self-testing apps?

Authors: Alexandra Kapeller, PhD student, Linköping University and Iris Loosman, PhD student, Eindhoven University of Technology

Abstract:
Self-testing apps offer users to self-test for various medical conditions. These direct-to-consumer apps are an emerging and increasingly popular technology. As part of the broader mobile health (mHealth) movement, they fit the development towards more access to exponential amounts of health-related information. Since such apps allow users to obtain medical information independently of professional healthcare, they are often marketed as empowering: "Empower yourself! Control your health!" Empowerment has become a key concept not only in self-testing and mHealth, but in healthcare in general. There, the WHO defines it as "a process through which people gain greater control over decisions and actions affecting their health".
In this article, we problematize the claim that an app is sufficient to empower users to achieve control over health decisions and actions. We do so by examining the notion of empowerment and show how, in literature and marketing material on self-testing apps, it is often formulated in terms of knowledge and control. We argue that this formulation of empowerment as a goal or end-state is blurry and one-sided. Through an analysis of promised and delivered knowledge and control, we show why a mere goal-oriented formulation fails to deliver the promised results: knowledge of something does not equal knowledge about what to do, and control over certain health decisions does not equal control over health. We argue that external factors, such as social support and access to healthcare, are always decisive for the empowering potential of apps. These factors, we observe, are considered in the process-oriented formulations of empowerment to be found in the general health empowerment literature and WHO definition. When such formulations of empowerment complement goal-oriented ones, the limitations of the apps can be made clearer: Self-testing apps can set people up for empowerment, but they cannot do so alone. We conclude this article by briefly suggesting several strategies to avoid creating false expectations and to at least increase self-testing apps' empowerment potential.

(95) Title: Ethical concerns in smart home technologies for caregiving purposes - a systematic review

Authors: Nadine Andrea Felber, PhD-Candidate, Institute of Biomedical Ethics, University of Basel, Angelina Tian, PhD-Candidate, Institute of Biomedical Ethics, University of Basel, Dr. PD Tenzin Wangmo, Senior Researcher, Institute of Biomedical Ethics, University of Basel

Abstract:
For an aging population worldwide that wishes to remain independent as long as possible, smart home technology might be a solution to make that wish come true. More specifically, smart home technology meant for caregiving purposes could allow older persons to manage their health in place and rely less on loved ones or professional caregivers. Nevertheless, while such technology may potentially enable aging in place (however this term should be defined), it also introduces plenty of ethical issues for older users, their relatives and professional healthcare personnel. To investigate these ethical concerns and their relevance in the current scientific literature, we conducted a systematic review of the empirical literature on the knowledge associated with their use for persons who are 65 years or older. We included empirical and theoretical peer-reviewed English, German, and French articles in ten electronic databases. Using narrative synthesis, we analyzed the data. A total of 158 included publications revealed 7 first-order ethical issues: 1) privacy, 2) autonomy, 3) responsibility, 4) trust, 5) human vs. artificial relationships, 6) social stigma and ageism, 7) other normative issues. Each category can be further divided into sub-themes which describe more specifically how smart home technologies meant for health and caregiving affected or interacted with the older persons, their family members, or healthcare providers. Overall, our analysis reveals a plethora of ethical concerns that primary and secondary users perceive in regards to smart home technology in the caregiving context, while normative publications are still rather scarce. Thus, our work gives a comprehensive overview of the current ethical landscape of smart home technologies for elderly users and can guide future research in addressing these ethical issues.

(96) Title: Electronic Tracking Devices for People with Dementia: A Content Analysis of Company Websites

Authors: Jared Howes, PhD candidate, Centre for Biomedical Ethics and Law - KU Leuven.

Abstract:
Background: Electronic tracking devices, also known as locators, monitors, or surveillance devices, are increasingly being used to manage dementia related wandering. To date, little research has focused on the companies responsible for the design and development of electronic tracking devices. Websites of commercial companies are often the first point of contact persons turn to for information about using these devices to help manage wandering; therefore, how companies portray various ethical concepts is relevant to gaining a holistic understanding of the broader context in which these devices are used. This article is the first qualitative analysis on the ethically relevant content present on websites of companies that design and develop electronic tracking devices.
Research questions: How do companies that design, develop, and market electronic tracking devices for dementia care frame, through textual marketing content, (1) the vulnerabilities and needs of persons with dementia and caregivers; (2) the way in which electronic tracking devices responds to these vulnerabilities and needs, and (3) the ethical issues and values at stake.
Methods: Two methodologies were employed. First, a systematic review of electronic tracking device company websites was performed. Second, using the Qualitative Analysis Guide of Leuven, a qualitative analysis was performed on the textual content of the 29 included websites.

Results: Electronic tracking device content currently excludes persons with dementia as a target audience, instead aiming content towards caregivers. Companies identify a range of inter-related vulnerabilities facing caregivers and persons with dementia that their products rectify through specific care tools aimed at bringing about a certain vision of life. In presenting this vision, companies link particular values to design decisions. For instance, privacy to intentional limitations in a devices' capacity to share information. Additionally, website content can be placed along three narrative continuums. Companies describe device capabilities and impact along an idealistic to realistic continuum, the approach to addressing the problems of wandering on a technical to human continuum, and articulation of the design process on a company-centric to co-creation continuum.
Conclusion: Further research is needed into the linking of values and intentional design decisions in electronic tracking devices for dementia care.

Parallel Session 3
Room 2PM
Chair: Bert Molewijk

(97) Title: The Art of Creating Dialogues in Clinical Ethics - How Systems Thinking Impacts Ethical Support Services and Complements Facilitation Techniques

Authors: Katharina Woellert, Scientist (Dr. phil.) and Head of Clinical Ethics, University Medical Center Hamburg-Eppendorf / Clinical Ethics Unit and Institute for History and Ethics of Medicine

Abstract:
Essentially, clinical ethics is about creating dialogues. Its formal target is to influence ethics quality in health care positively. Specific methods and approaches are needed depending on the respective field of activity. Ethics case consultation requires different techniques than, for example, ethics training. But it is always about forming spaces for ethical reflection or creating dialogues about moral issues.
For this purpose, clinical ethics must be based on complex competencies. In addition to well-founded knowledge of ethics, mastering suitable consulting methods is an indispensable prerequisite. It requires a targeted and theory-based use of consulting methods. The scientific discussion is essentially limited to the design and the process of ethics interventions. It is about structures that help analyse and discuss complex ethical dilemmas. However, one essential aspect remains untouched. This is the question of the appropriate consultation technique, i.e. tools to steer a group through a reflection process.
In this presentation, I will take up this rarely discussed aspect while using the hypothesis that systems theory and systems thinking make a central contribution to clinical ethics support services. After a brief insight into systems thinking, I will discuss the possibilities that systemic tools offer to the challenges of clinical ethics support services. This will be elaborated using theory-guided case reconstruction of ethics case consultations. The evaluation is part of a broader study of basic systemic assumptions and methods for clinical ethics. It aims to identify paradigmatic dilemmas and reflection constellations. In this presentation, I will use sequences of the reconstructed processes to demonstrate the possible effects of systemic interventions, such as clarification of mandates, circular questioning techniques or guidance on complexity expansion. I will argue that an even stronger focus on methodological details is needed. Besides the what, above all, it is about the how of ethical reflection and thus about the design of reflection processes. This presentation is intended to sharpen attention to the conscious use of facilitation techniques.

(98) Title: Ethics Rounds, a multidisciplinary, dialogical experience to integrate ethical reasoning into clinical clerkship

Authors: Prof. Yesim Isil Ulman, PhD, Prof. Pinar Topsever MD, PhD, Gokberk Zeybel, Mustafa Ege Seker; Acibadem University School of Medicine

Abstract:
Overall process of medical education is regarded as a form of moral training of future doctors who will provide healthcare, prioritize the patient's welfare, remedy the sick responsibly, compassionately and virtuously. In fact, learning environment of medical education has both positive and negative influences on student's acquisition of ethics-related knowledge, skills and attitudes. However, innovative educational practices have demonstrated that ethics can be better and more efficiently taught by practice in order to develop skills in detecting the presence of ethical dilemmas, resolving problems, conducting ethical reasoning, understanding of the concepts of ethics to achieve transformative learning, eventually.
This paper aims the retrospective analysis of the ethics rounds practice during the clerkship training in terms of knowledge and skills of ethical values and decision-making all through nine years at the School of Medicine. The ethics rounds are educational intervention to incorporate medical ethics training as a part of students' professional development within the context of clinical training. They are organized within the internal medicine clinical clerkship which takes place four times within the academic year, rotating groups of students in an interdisciplinary manner with clinicians from various branches. The clinicians are asked to choose a case representing an ethical dilemma from their daily clinical practice. They are provided with a guide to prepare this case for discussion during the session. The format of this guide includes a short case description, formulation of the problem and identification of the related ethical values and/or principles.
The students describe session as beneficial, remindful, stimulating; propose repeating these exercises in each clinical year; like to work on cases from the real daily clinical practice; enjoy to express their views openly with peers , clinicians and instructors.
In conclusion, Ethics Rounds are sustainable and compatible with the vertical integration in medical education to enhance ethics-related skills and professionalism. It not only helps moral development of medical students and involve them in clinical, ethical decision-making, but also equips them with the ability to understand complex situations and resolve them in a self-critical, dialogical, peer-learning style as well as allowing young residents to consolidate ethical reasoning skills.

(99) Title: Ethics consultation, educational programs, and institutional policies: a preliminary report of a Clinical Ethics committee's activities one year since implementation.

Authors: Perin Marta (PhD candidate, 1.Bioethics Unit, Azienda USL-IRCCS di Reggio Emilia; 2. PhD Program in Clinical and Experimental Medicine, University of Modena and Reggio Emilia) and De Panfilis Ludovica (PhD, Bioethics Unit, Azienda USL-IRCCS di Reggio Emilia) on behalf of the the Clinical Ethics Committee, Azienda USL-IRCCS di Reggio Emilia.

Abstract:
A Clinical Ethics Committee is a multi-professionals service that aims to support health care professionals in dealing with complex clinical cases,

characterized by conflicting ethical perspectives through ethics consultation. Users, especially physicians, generally appreciate Clinical Ethics Committee's ethics support. However, difficulties remain regarding how to evaluate the service's effectiveness. A better description of the intervention's development and implementation has been required to develop an appropriate evaluation process.
In October 2020, a Clinical ethics committee was implemented at the Oncology Research Hospital of Reggio Emilia in North Italy following the 2017 Italian National Committee for Bioethics guidelines. It is currently undergoing a research project evaluating the implementation process. Here we present the preliminary data collected during the first year of the service's activity (October 2020- 2021).
The PI of the project collected quantitative data related to the implementation process and the activities provided by the service in a specific database and organized them into a report to provide a comprehensive description of the whole process.
The service, named Comitato per l'Etica nella Clinica (CEC), is composed of 15 members, 6 external and 9 internal to the hospital. It has a Secretariate and a President who coordinates the activities. In total, the CEC performed 10 meetings and:

- provided 4 ethics consultations (concerning respectively: a pediatric case, a family disagreement regarding the Covid-19 vaccination, the compassionate use of a medical device, and the administration of unconventional therapy);
- published 3 policies related to particular ethical questions of clinical and organizational practice;
- provided 8 hours of training online course on Ethics Consultation targeting local employed health care professionals. Participants were 161 among different professional figures;
- promoted a specific dissemination process among the hospital's different departments.

More details on the activities will be reported at the Congress. Our data may increase knowledge regarding the composition, role, and tasks of a clinical ethics consultation service in an Italian setting, informing future strategies and efforts to regulate these institutions officially. Further investigations are needed to evaluate the CEC impact on HPs' knowledge and its related implications in clinical practice.

(100) Title: By physicians for physicians - developing a 'first aid scheme' for ethical decisions in erveryday clinical practice

Authors: Cand. Dr. med. Michael Buzzi and Prof. Dr. Rouven Porz, Medical Ethics Unit, University Hospital of Bern, Medical Faculty, Bern, Switzerland

Abstract:
In the context of clinical ethical support, MCD (moral case deliberation) is a well-known method in Europe for conducting ethical case discussions (Molewijk and Widdershoven). MCD is successfully used to manage ethically difficult clinical situations. To us, this method seems sensible and suitable, so we have started our own reflections based on our clinical experience with MCD.
The aim of our study, however, was to develop a simple low-threshold ethical orientation tool, focus: by doctors for doctors. This is mainly because our clinical experience in conducting MCD has shown us two things: First, MCD as an interdisciplinary deliberation is always associated with a significant expenditure of human resources. And secondly, especially young doctors who are completely new in their daily work may not always dare to convene an MCD directly for every difficult ethical situation that they encounter.
So, we wish to demonstrate our ideas of a 'first aid scheme' in ethics deliberation, especially tailored for young physicians, in order to provide those with initial orientation in ethically challenging situations (and/or to enable them for good preparation for an upcoming MCD).

(101) Title: Sharing the moral dialogue – investigating the intricacies of patient and family involvement

Authors: Dr. Janine de Snoo, Dr. Mira Vegter, Savannah van Kuppenveld, Dr. Margreet Stolper, Prof. Dr. Bert Molewijk

Abstract:
Ethical issues in healthcare often concern individual patients and their families. Although patient and family participation is considered to be of high importance in healthcare - illustrated by the growing attention for Shared Decision Making - it is not common to involve them in clinical ethics support activities such as Moral Case Deliberation. The involvement of patients and family is of high importance in the delivery of patient-centered care as well as in the improvement of the quality of care by learning from experiences of both professionals and patients, or family of patients. Our project aims to strengthen shared reflection on moral issues and questions in ethics support by means of the development of guidelines and the adjustment of existing ways of doing clinical ethics support or the development of new ones. We do not mean to imply that patient and family participation should be dogmatically incorporated in clinical ethics support. Rather, we aim to investigate when this would be the right thing to do and when there are compelling reasons to refrain from it. There can be practical objections, conceptual confusion or normative disagreement. This includes concerns about harming the patient-physician relationship by letting one perspective overwhelm or overrule the other. In addition, a conceptual concerns involves the question of what 'participation' actually means and moral challenges involve questions such as "Is patient and family involvement a duty or an opportunity?".
We will conduct a literature review as well as semi-structured interviews with patients and family, healthcare professionals and clinical ethics support staff, in close collaboration with stakeholders of three diverse departments of Amsterdam UMC. By investigating concerns, objections, questions and best practices of patient and family involvement in ethics support we lay the groundwork for actually sharing the moral dialogue among all these parties. We will present our preliminary findings and insights. Furthermore, we will provide an outlook on the next steps in our project, to ultimately develop innovative forms and supportive tools for establishing a shared moral dialogue in which patient, family and care providers are equally involved.

Parallel Session 3
Room 6MTG
Chair: Emma Capulli

(102) Title: Secondary research use of personal medical data: Patient attitudes towards data donation

Authors: Gesine Richter, M.A. MBA1, Christoph Borzikowsky, PhD2, Bimba Franziska Hoyer, MD3, Matthias Laudes, MD4, Michael Krawczak, M.Sc. PhD2 1 Institute of Experimental Medicine, Division of Biomedical Ethics, Kiel University, University Hospital Schleswig-Holstein, Kiel, Germany 2 Institute of Medical Informatics und Statistics, Kiel University, University Hospital Schleswig-Holstein, Kiel, Germany 3 Department of Internal Medicine 1, University Hospital Schleswig-Holstein, Kiel, Germany 4 Division of Endocrinology, Diabetes and Clinical

Nutrition, Department of Medicine 1, University Hospital Schleswig-Holstein, Kiel, Germany

Abstract:
Background: The SARS-CoV-2 pandemic has highlighted the need for comprehensive access to patient data for medical research. Such secondary data use is a prerequisite for translation and personalisation in medicine, and for public health. Balancing scientific interest and a demand for individual autonomy, privacy and social justice is a great challenge for patient-based medical research. Considerations got under way of a legal basis of data donation in Germany. Previous studies suggested acceptance of data donation, but had not differentiated the legal and organizational concept in detail yet.
Methods: We conducted two questionnaire-based surveys among North-German outpatients (n=650) to assess their attitude towards data donation for medical research, implemented as an opt-out process (i.e. legal permission of data use unless actively denied).
Results: We observed great acceptance of data donation (75.0%) mainly due to the conviction that every citizen has a duty to contribute to medical research (>80% of those approving data donation). Patients distinguished sharply between research inside and outside the EU, the willingness to allow data use by commercial research was low (companies located outside EU: 7.1%, in Germany: 29.1%). The most popular measure to counteract such reservations was regulation by law (61.4%), stipulating that data are not sold (84.6%). A majority requested independent control of data use (46.8%) and data protection (41.5%).
Discussion: We identified reasons for reservations about commercial research with donated data and corresponding counteracting measures, useful designing a data donation process. Most frequent concerns were insufficient data protection by commercial users and an objection of their profit-making through the use of the data, explaining the demand for a legal ban on commercializing the data. Data donation for medical research, implemented as a legal entitlement with easy-to-exercise opt-out, is supported by German patients and therefore warrants further considerations of the implementation modalities. Our observations significantly contribute to the question of broad bioethical education. The question arises as to whether the automatic sharing of medical data for research purposes without consent, which is seen as a general (passive) duty, is accompanied by the acceptance of an active moral-ethical duty of every citizen to increase one's own health-data-literacy.

(103) Title: How should we define 'everyday ethical challenges' in older adult care research?

Authors: Kumeri Bandara, PhD Candidate, University of Oxford

Abstract:
Finding a definition for 'ethical challenges'—let alone 'everyday ethical challenges'—on which researchers agree is impossible. Existing literature is scattered with definitions of ethical challenges that range from moral uncertainty, difficult decisions, and moral dilemmas to moral conflicts. Further, whichever definition scholars use, there are also differences in how care workers on the ground understand and interpret the expression. This is especially salient given that care workers rarely think about their actions and decisions in 'ethical' terms. Another complication is that there is a possibility for care workers' interpretations of what counts as an 'everyday ethical challenge' to be different from that of scholars or even other care workers. As researchers working in older adult social care in different countries have noted, even seemingly straightforward terms such as "abuse", "poor practice", and "violence" are interpreted and used differently by care workers, which further complicates the definitional challenges that researchers in this area face. In this paper, I discuss how to best define 'everyday ethical challenges' in a way that is accessible and useful to both scholars and practitioners in the field of older adult care work. I do so by engaging with empirical findings from fieldwork carried out in 2022. My fieldwork involves interviews with migrant and local care workers, other employees, and managers in care and nursing homes in the UK; and personnel related to the governance of older adult care in the UK. Gathering input from such a professionally, culturally, and nationally diverse demographic ensures that this account of 'everyday ethical challenges' is grounded in the specific challenges that care workers and other stakeholders in the field describe, and aims to be responsive to the precise words and phrases that they invoke to describe and make sense of these challenges.

(104) Title: Let's bridge the gap: Why public health research papers should entail the transparent use of bridge principles when recommending moral actions

Authors: Katja Kuehlmeyer *, Institute of Ethics, History and Theory of Medicine, LMU Munich, Germany (Presenter); Marcel Mertz , Institute of Ethics, History and Philosophy of Medicine, Hannover Medical School, Germany; Joschka Haltaufderheide, Institute for Medical Ethics and History of Medicine, Ruhr-University Bochum, Germany; Alexander Kremling, Institute for History and Ethics of Medicine, Interdisciplinary Center for Health Sciences, Martin Luther University Halle-Wittenberg, Germany; Sebastian Schleidgen, Institute of Philosophy, FernUniversität in Hagen, GermanyJ; Julia Inthorn, Center for Health Care Ethics [Zentrum für Gesundheitsethik], Germany

Abstract:
New knowledge in public health is gained, to a large extent, through empirical research. This knowledge is the basis for decisions for future actions or recommendations in order to pursue goals such as promoting health and lowering unjust health inequalities. Publications of empirical public health research thus often entail recommendations for moral action that address practitioners and policy makers. These recommendations are regularly not only based on the explicit empirical results, but also on implicit moral judgments – without explaining the connection between these two types of information. One reason for this lack of transparency is that the link between the description of empirical results and the normative or evaluative conclusions of the research report is rarely reflected upon in the research methods literature.
Therefore, we elaborate on the methodological relevance of explaining underlying moral judgments in research articles in order to account for academic argumentation. We then argue for an explicit reporting of so-called bridge principles to increase the transparency of the reporting of public health research. Bridge principles are rationales that are used to combine empirical results and normative or evaluative conclusions, and are based e.g. on a means-end relationship, a comparison with analogous cases or an ought-implies-can rule. The accurate reporting of BPs used can inform readers, support them in understanding the relationship between the empirical results and recommendations in a specific paper, and may pave new ways for the rigorous reporting of empirical research that has moral implications. Furthermore, BPs can be used to classify studies in order to systematically address the justification for their argumentation, as the specific use of bridge principles can be more or less convincing. While there are also limits to the usefulness of BPs with regard to the quality of a recommendation, we illustrate the relevance of BPs in public health research by using examples of COVID-19 research.

(105) Title: Why selective contracting and budget policies are not morally defensible. A critical analysis from moral and institutional theory

Authors: Stef Groenewoud

Abstract:
In demand-oriented health care systems that are based on principles of managed competition, health care insurers are expected to be prudent purchasers on behalf of their enrollees by selectively contracting care providers that add value for patients. Health care insurers in the Netherlands, have grown into this role since the Healthcare Insurance Act came into effect in 2006.
During the past five years the number of enrollees with policies with restrictive conditions (so called 'budget policies') increased from 2.27 million (13.1%) in 2017 to 3.19 million (18.4%) in 2021. In a recent study 70% of the budget policy holders reported that they were satisfied with their current policy. Based upon such data, one may conclude that budget policies match people's needs and are therefore an important asset to our health care system.
However, if we delve a little deeper into the backgrounds of managed competition and selective contracting, the moral justification for budget policies turns out to be quite more difficult. In this paper we address the question whether, or under what circumstances selective health care contracting would be morally defensible.
We use the (moral) principles of 'freedom' and 'efficiency' that are often seen as the major advantages of commodification of health care and its distribution through the market. To these, we add the concept of 'equity' as a kind of lower limit because most people do share the premise (either principally or pragmatically) that a health care system should at least be equitable.
Based upon a thorough analysis of the aforementioned principles, and using empirical data on the functioning of the Dutch health care insurance market, we draw the conclusion that in its current form, selective contracting and the phenomenon of budget policies are not morally defensible and should (at least for large parts of health care) be reversed into other forms of health care purchasing and optimization.

Poster Presentations

(106) Title: Genetic data, from human heritage to national resource

Authors: P. Bailo 1, A. Piga 1, F. Gibelli 2, A. Blandino 1, G. Ricci 2, A. Sirignano 2, A. Piccinini 1, R. Zoja 1; 1 Università degli Studi di Milano, 2 Università degli Studi di Camerino.

Abstract:
Genetic data has always been in the spotlight from a legal and ethical point of view because of its nature which allows concrete possibilities of discrimination. Article 1 of the Universal Declaration of the Human Genome and Human Rights of November 1997 states that "In a symbolic sense, it is the heritage of humanity". In fact, the interests of the subject to whom the genetic data "belong" has been defended by all national legal systems and all international and ethical regulations.
A balance between private and public interests (scientific research, public safety) has often been found, even in difficult court cases. However, new issues now arise after the Popular Republic of China identified genetic data as a national resource with the publication of a "Regulation on the Management of Human Genetic Resources". Given this new approach, will the privacy and rights of those providing the genetic resource be respected? Or does this initiative represent not only a prelude to issues of consent and privacy, but also to new and troubling phenomena such as genetic surveillance and marginalization/exploitation of genetically identified minorities?
The purpose of our research is to analyze the ethical and legal consequences of nationalizing genetic data, taking into account the shift in perspective between the individual and the state as "owner" of the data.

(107) Title: Teaching ethics via Moral Case Deliberation with data engineering students during the pandemic: a case-study

Authors: PD Dr. Barbara Buchberger Institute for Health Care Management and Research, University of Duisburg-Essen, Germany; Simon Witzke, Fabian Lange, Fabian Galandi, Malte Barth, Paul Wullenweber, Leo Wendt, Julian Zabbarov all Hasso-Plattner-Institute, University of Potsdam, Germany

Abstract:
Background: Moral case deliberation (MCD) was part of an ethics module for data engineering students during winter semester 2021/22. After introducing ethics and moral theories, the MCDs aimed at stimulating moral learning by exploring other perspectives.
The case is exemplary for students during the pandemic who must restrict their leisure time behaviour to protect vulnerable relatives and friends. As member of a football club, Julian trains up to three times a week. His dilemma was: either going to a boisterous football team party with increased alcohol consumption and no compliance with distance rules (option A) or cancelling the party following an invitation from his vulnerable girlfriend and grandparents a few days later, without fear of infecting them (option B). We aim to highlight moments during the MCD and describe its value as perceived by the group.
Methods: A full MCD was carried out.
Results: Damage following option A was identified as illness of girlfriend and grandparents, feelings of guilt, loss of trust and reputation, and fear of infection. Expected damage of option B were sadness, lack of social exchange and participation, and less or no camaraderie and sense of belonging. For the technical- and application-oriented students, identifying values and corresponding norms was challenging. Creativity emerged in the individual decisions for one option, particularly for the possibilities to limit the damage and therefore necessary means. All chose option B and solidarity as primary value, and real-life solutions to limit the damage, like kicking around in the park together or promising a crate of beer, were found.
Discussion: In the evaluation, the students noted that putting values and norms into concrete words and making them visible to all helped to focus the issue at stake and to identify actual and potential points of conflict. The input from all participants has shown the value of gaining different and new perspectives on a dilemmatic situation. Criticism of the time required was also voiced.
Conclusion: Due to its structured approach, MCD is well-suited to teach ethics to data engineering students. They are thereby trained to concretely reflect on ethical dilemmas they encounter in practice.

(108) Title: Disability or disease in mental health: who are classification systems for?

Authors: PD Dr. Barbara Buchberger, Vivien Raczkiewicz Institute for Health Care Management and Research, University of Duisburg-Essen

Abstract:
Background: Presented are two young people whose language and linguistic development is comparable but not age appropriate. One was born with Down Syndrome which is classified as 'Congenital malformations, deformations, chromosomal abnormalities' (Q90) according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and is considered a mental disability. The other was diagnosed with mild mental retardation which is classified as F70 under 'mental and behavioural disorders', a mental illness. The latter seems to indicate a malfunction or disturbance which may be somehow cured or corrected, whereas Down Syndrome as congenital abnormality sounds like a status one must come to terms with. This interpretation is supported by the entry for F70 in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) edited by the American Psychiatric Association, which is Intellectual Developmental Disorder. Down Syndrome as congenital abnormality has no entry.
Our aim was to investigate whether selected translations help to improve the understanding of the Q and F classifications of ICD-10, and whether ICD-11 will represent further development.
Methods: Descriptive analysis by comparing conceptual attributions in ICD-10, DSM-5, and ICD-11 in five Central European languages.
Results: Our comparison revealed that the ICD-10 classifications F70-79 show serious semantic differences between countries. The English classification 'mental retardation' is the same in the Romance languages Italian, Spanish, and French, but the German and Dutch terms show a different understanding with 'intelligence reduction' and 'feeble-mindedness'. Concerning the F80-89 classifications, the descriptions fluctuate between psychic and psychological disorders. There are no changes regarding those inconsistencies in the new version of ICD, but the descriptions of F-diagnoses are more specific, which may result in more target-oriented therapies.
Discussion: The manifestation of disease is the same in both cases presented, but the classifications differ with possibly stigmatising effects for those who are affected. The different conceptual attributions also generate different expectations of relatives, caregivers, treating physicians, and in society leading to different needs being defined. Therefore, the title question remains open who classification systems are for.

(109) Title: Becoming a competent Biobank Ethics Consultant: skills, roles and training

Authors: Elena Ferioli, Biologist PhD - Center for Clinical Ethics, Department of Biotechnology and Life Sciences, University of Insubria

Abstract:
Biobanks are large-scale repositories of biosamples and associated data and this unique combination makes biobanks very special regarding their position in biomedical research, ethical requirements, multidisciplinarity and international collaboration.
In recent years the Research Center of Clinical Ethics of Insubria University consider that it would be interesting to design a biobank as a key research infrastructure which must respond to high quality levels, safety and skills as required by the international community and to set up an appropriate ethical framework identifying sufficient and well-established ethical instruments avaible for regulating biobank research.
Many academic medical centers have created formal research ethics consultation with a goal of addressing the ethical, societal, and policy considerations associated with biomedical research and a number of these programs are modelled on institutionalized clinical ethics consultation services, but could therefore need a more specific progress direct to research increasingly carried out in biobanking.
For this reason the Research Center of Clinical Ethics wants to propose the institution of a Biobank Ethics Consultation Services to help scientists, health care professionals, patients, donors and institutional review board navigate the specific ethical issues in biobanking management and research.
Hopefully this special ethics consultation should be integrated into a bioethics service with a dedicated ethical consultant. Credentialing of biobank staff will become important as biobanking becomes professionalized and the presence of a biobank ethicist will be essential to support such credentialing and to offer practical, tangible and hands-on ethical and legal guidance.
The credibility and effectiveness of biobank ethicists depend upon their knowledge about moral arguments, the law, public opinion, and so on, as well as the skill to use that knowledge to help others make decisions.
Just as for clinical ethics consultation, the question of whether there is a set of core competencies that each consultant should possess needs to be answered and therefore preliminary recommendations for activities, expertise, skills and knowledge are presented in this study.

(110) Title: Will they follow my parents and treat me against my wishes? A case-based reflection about autonomy in pediatric advance care planning

Authors: Kathrin Knochel, MD1,2, Monika Führer, MD2, Alena Buyx, MD1, Georg Marckmann, MD3 1 Clinical Ethics, Institute of History and Ethics in Medicine, Technical University of Munich, School of Medicine, Munich, Germany 2 Center for Pediatric Palliative Care, Dr von Hauner Childrens Hospital, University of Munich, Munich, Germany 3 Institute for Ethics, History and Theory of Medicine, University of Munich, Munich, Germany

Abstract:
Background: Advance care planning is a concept supporting patients' autonomy. It is a process preparing future decision-making using conversations about individual goals of care and balancing benefits, risks, and consequences of treatment options. Advance care planning conversations aim at empowering persons for shared decision-making and at ensuring that surrogates are informed about wishes and preferences for situations when they are not able to speak for themselves.
Main text: A 14yrs adolescent who was capable to make medical decisions asked her physician to make an advance directive for limiting treatment in case of future progression or crises of her advanced neuromuscular disease. She was already dependent on mechanical ventilation, lived at home with her family and did not want to move into a care facility. Considering the values of her Yazidi family, she worried that her parents would not respect her wishes and emergency physicians could decide with them to continue life-sustaining treatment against her advance directive. The following family meetings to discuss her preferences allowed to make some agreements, but also showed limits of her parents to talk with her about her disease and to respect her wishes. The conflict was deeply reinforced a few years later when she started to think about withdrawal of mechanical ventilation to die. The dilemma, that for cultural reasons her family would never respect her wish to die, while she wanted to continue to be supported and cared for by her family, was challenging for all persons involved.
Applying the principle of autonomy in this case requires a reflection of the complex interplay between patient- and family-centered decision-making: How can the autonomy of an adolescent patient be realized given her physical and emotional dependencies and her dilemma to choose between own preferences and family support near the end of life?

Conclusion: Realizing care according to adolescent patients' best interests may require careful balancing of the minors' autonomy and parental decisional authority. Advance care planning is a tool to empower young patients to develop and discuss their preferences with their families and caregivers. This deliberative process can support balancing patient- and family-centered decision-making.

(111) Title: Nothing about us without us? The ethics of participatory research with Deaf people – a research plan

Authors: Tomasz Krawczyk, MA, Department of Philosophy and Bioethics, Faculty of Health Sciences, Jagiellonian University Medical College

Abstract:
Deafness, traditionally considered a medical condition (disability), in last decades has also been acknowledged as a socio-cultural phenomenon. Therefore, inclusion of Deaf people into research requires researchers to implement additional means for assuring full participation. These issues are of particular importance within the use of participatory research methodology, which gains popularity across various scientific disciplines. This methodology, based on partnership in the involvement of participants, increases opportunity for mutual understanding. However, the challenges of ethical engagement of participating groups remain. Within the context of Deaf people, they are additionally extended by the complexity of the situation, as perspective on deafness is diverged around the world and among disciplines.
The aim of my research plan is to investigate how to engage ethically Deaf people into participatory research. I will pay attention to research partnership, participation within research process and spreading the results of research and its impact on the community. Moreover, I will investigate interdisciplinary differences, alongside with researchers' perspective on deafness and Deaf people research experiences.
To investigate these issues I will use an empirical ethics methodology, situated within the Mapping-Framing-Shaping framework. Firstly, the state of the art will be examined with two systematic reviews, prepared with accordance to the PRISMA statements, on the topic of Deaf people in participatory research. The first one will investigate empirical research in health, social sciences and humanities, while the second one will investigate existing normative research and guidelines. The second step will deepen outcomes of the reviews with in-depth interviews conducted with researchers and Deaf community members. Finally, outcomes from both steps will be used to prepare ethical recommendations for scientific cooperation between Deaf people and researchers from various disciplines, with special focus on participatory research methodology.
The proposed study will contribute to the inclusion of Deaf people in research, broadening the perspective on deafness within researchers, as well as mitigating prejudices of Deaf people about science and research process. It could help to bridge the gap between science and diverse contemporary society. By sharing and exchanging research experiences, it could also contribute to the integration among scientific disciplines.

(112) Title: Transplantation and minors: ethical, deontological, and medico-legal aspects

Authors: Francesca Maghin 1; Paola Delbon 2; Adelaide Conti, 1,2; 1 -Forensic Medicine Unit, Department of Medical and Surgical Specialties, Radiological Sciences and Public Health, University of Brescia & ASST Spedali Civili of Brescia, Piazzale Spedali Civili 1, 25123, Brescia, Italy; 2 Centre of Bioethics Research, Department of Medical and Surgical Specialties, Radiological Sciences and Public Health, University of Brescia, Piazzale Spedali Civili 1, 25123, Brescia, Italy.

Abstract:
In the field of transplantation and minor it is necessary to distinguish the cases in which the child is the recipient of the donation from the one in which he/she plays the role of potential donor.
In the first case, the transplant should be considered as any medical treatment. Nowadays, there is an increasing focus on the rights of the minor patient and his/her decision-making autonomy (Law no. 219/2017). The physician must determine how to inform the minor about his/her state of health and the diagnostic and therapeutic treatments to which he/she will be subjected, listening to his/her opinion and wishes, although these have no legal value. The decision on informed consent or dissent to diagnostic procedures and/or therapeutic interventions shall always be taken by the parents as the holders of parental responsibility or, in the absence thereof, by the legal representative.
Different problems arise when considering the minor as a potential organ donor. In the case of minors, the current legislation (Law no. 91/1999) does not allow the possibility of registering the "declaration of will", that all citizens of age are required to provide, regarding the donation of organs and tissues of their body after death. Moreover, it is problematic to determine what value should be attributed to the will possibly expressed in life by the child, whether it is against/in favor of organ donation. In any case, the law reserves the power to parents to consent or to oppose the donation, in case of cadaver transplantation, even if the minor donor has expressed a different will. As a result, the autonomy of the child, whose "will" is not taken into account, is sacrificed. In the case of a living transplant, only the donation of cells or tissues is permitted after the consent of those exercising the child's power. Therefore, even in this case, the will of the child, possibly in contrast to that of the parents, is not considered relevant.
In this intervention, ethical, deontological, and medico-legal aspects are considered in relation to the issue of transplants in which minor subjects are involved.

(113) Title: Ethical issues surrounding compulsory COVID-19 vaccination in young adults pursuing solid organ transplantation

Authors: Manfrin Elia 1, Redaelli Pietro 1, Burlando Matteo Luca 1, Grossi Alessandra Agnese 2; 1 Resident in Legal Medicine, University of Insubria, Varese, Italy; 2 Center for Clinical Ethics, Department of Biotechnologies and Life Sciences, University of Insubria, Varese, Italy.

Abstract:
The ongoing coronavirus disease (COVID)-19 public health emergency has had a major impact on children and young adults (age-range 5-16 years) with chronic conditions, including solid organ transplant (SOT) recipients. To mitigate the risk of acquiring the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) infection, one of the most effective yet debated strategies is the vaccination against COVID-19. For instance, although immunocompromised patients may experience a decreased immune response, evidence shows that vaccination has some benefits by reducing the risk and severity of COVID-19 in this vulnerable group of patients.
Two SARS-CoV-2 mRNA vaccines have been approved for the prevention of COVID-19, with a vaccine efficacy of 95% in the immunocompetent population. However, many transplant recipients still fail to produce

antibody response even after receiving a third dose of a COVID-19 mRNA vaccine. Therefore, despite the paucity of data, vaccination of transplant candidates (i.e. prior to receiving SOT) has been strongly recommended by scientific societies because recipients may be at increased risk of severe SARS-CoV-2 infection with post-transplant immunosuppression. However, this has raised the question of whether or not it is ethical to require compulsory COVID-19 vaccination for children and young adults to be enrolled on transplant waiting lists. As a result, the demand for COVID-19 vaccination as a mandatory requirement for SOT candidacy is heterogeneous across different countries and even across transplant centers in the same country. This is especially relevant in the event of parental vaccine hesitancy. Because this is an emergent issue and the debate is ongoing, this contribution aims to examine the relationship between mandatory COVID-19 vaccination and SOT candidacy in children and young adults pursuing SOT. To provide ethical arguments in favor and against the denial of SOT in the absence of COVID-19 vaccine in this group of patients, we reviewed the literature to collect evidence of outcome data relative to graft and patient survival prior to and after the introduction of SARS-CoV-2 mRNA vaccines in children and young adults who received SOT; vaccination-related risks in children and young adults; and the risks of delayed SOT across different organ settings.

(114) Title: Wearable Devices and Bioethics, a review of the literature

Authors: Martino Maesani 1, Maria Manno 1, Fabrizio Cordasco 1, Matteo Antonio Sacco 1, Carmen Scalise 1, Angelica Zibetti 1, Umberto Rosini 1, Saverio Gualtieri 1, Giulio Pulpito 1, Alessandro Tarallo 1, Vincenzo Ritorto 1, Cristoforo Ricci 1, Eva M. Kereszty 2, Santo Gratteri 1, Pietrantonio Ricci 1, Isabella Aquila 1; 1Legal Medicine Institute, Departement of surgical and medical sciences, University "Magna Graecia" of Catanzaro (IT); 2 University of Szeged, Hungary

Abstract:
INTRODUCTION: The digital revolution, and the rise in popularity of affordable wearable digital devices, has put in the forefront of new technology adoptable in medicine the use of said devices to achieve a variety of different purposes.
From least invasive constant Blood Pressure, glycemic level and Atrial Fibrillation monitoring, to health monitoring during the COVID-19 pandemic and possible public health intervention of lifestyle modification; this new field of technology poses a great deal of possibilities for clinical applications and also an amount of possibile doubts in the bioethics aspect of the situation.
MATERIALS AND METHODS: A review of the literature present in the databases: Pubmed, Medline, Scopus and DeJure, was performed entering the keywords: wearable, devices, fitness, blood pressure, atrial fibrillation, cardiovascular, health, COVID-19, ethics and byoethics.
DISCUSSION: This work will attempt to distill and summarize the known bioethical facets (both problems and possible solutions) presented by the application of wearable devices in the aforementioned fields. An attempt will also be made to uncover and shed light on possible new scenarios posed by these devices, and the big data industry in general, to bioethics expert.The surge in wearable technology applications can not just be seen as a mere passing trend, as such, bioethics scholars can't let themselves be found unprepared without a deep understanding of the intertwinings and connections implied in this field.
This work attempts to function as an entry point for newcomers, trying to give an overview of the bioethics implications connected with the use of wearable devices.

(115) Title: On Social Psychopathology in Context of Medical Philosophy and Law: Example with German Justice in COVID-19 Pandemic Times

Authors: Michael Ch. Michailov1, Eva Neu1, Angel Gherzikov1,2, Christoph Luetge1,3, Claude Gibault-Martin1,4, Iva Ivanova1,2, Marie-Luise Gräfin Brockdorf1, Janka Foltinova1,5, Michael Schratz1,6, Germain Weber1,7 1 Inst. Umweltmedizin c/o ICSD/IAS e.V., POB 340316, 80100 Muenchen, Germany (Int.Council Sci. Develop./ Int.Acad.Sci. Berlin-Bratislava-Innsbruck-Muenchen-New Delhi-Paris-Sofia-Vienna) 2 IUM Sektion Sofia-Kazanlak, Bulgaria 3 Techn. Univ., Inst. Ethics Prof. Dr. (Dir.), Muenchen, Germany 4 IUM Sektion Paris, France 5 Univ. Bratislava, Fac. Med., Prof.Dr.med., Dir. IUM, Bratislava, Slovakia 6 Univ. Innsbruck, School of Education, Prof. Dr. (Dean), Innsbruck, Austria 7 Univ. Luxemburg&Vienna, Fac. Psychology Prof. Dr. (Dean), Austria

Abstract:
INTRODUCTION. Similar to philosophy (regina-scientiarum) is psychiatry fundamental discipline for all medical&social sciences. Immanuel KANT (primus inter pares with ARISTOTELES&PLATON) considered over 200years ago physiological&pragmatic anthropology-[1]. Kant summarized philosophical questions "Was können wir wissen? Was sollen wir tun? Was dürfen wir hoffen?" related to social physiology [3-4] in the fundamental question "What is the human?". New conception about integral anthropology considers human interaction with nature/society/supra-nature (Table). Social-psychopathology in German-justice [2] has to be discussed in this context with importance for pandemic time.
METHODS. Consideration of information about persons in German juridical-bodies: philosophical, psychological, psychiatric approaches (ref.)
RESULTS Prominent German experts for justice: Patrick BUROW, Jens GNISA/President Law-Association/Germany, Ralph KNISPEL/Oberstaatsanwalt Berlin, Torsten SCHLEIF/Amtsrichter, Hans-Jochen VOGEL/Ex-Minister, Stephan ZANTKE/Richter reflect in their books fundamental-criticism of German justice [5a: Books]. Inst.-Ecol.-Med./IUM investigated psychopathology of district courts in Munich (Amtsgericht/AG-M, Landgericht/LG-M). Analysis suggests presence of symptoms for pseudologia phantastica (A), psychopathy(B), cyclophrenia, esp. mania (C), etc. conc. observations on many persons (n>30). Examples are to be discussed.
A. Pseudologica fantastica (Delbrück)
    1. Judge (AG-M/female) lying during processes-[5c-e].
    2. Administration of resident-house/RH in Munich disturbed domestic-peace (trespassing "Hausfriedensbruch") in year 2000, but denied during an process 2017: 3-Lawyers of tenant-organization (Mieterverein-München) contradicted this false information-[5b-d].
    3. Judge (LG-M,female), similar to example 1, contradicted the truth-[5f].
B. Psychopathia
    1. Lawyer described a medical-doctor (research) as "not normal", ignoring publications of this scientist in this field-[5c,d].
    2. Colleague of 1. tried many years by psychological-violence to eliminate 2-scientists from their apartments in RH by concealment of information, doubting of existent of a scientific organization and publication threatening with imposing of punishment up to 250,000 Euro (unclear juridical situation)-[5c,d].
    3. RH-Administrators tries 5years, supported by lawyers, to eliminate tenants (see 2.) - one invalid (over 68 years), one senior

(over 88years), both with complex pathology (attests from over 10medical-practices). Also over 10lawyers helped to protect the tenants-[5b,c].

C. Cyclophrenia

Analysis of information about persons working in juridical offices suggest symptoms of cyclophrenia, esp. mania.

1. Lawyer(see B.2.) is probably a querulous person, self-reliant, arrogant, i.e. psychopathy with symptoms of hyperthymia-[5c,d]!
2. Also information about disastrous process in German court in Munich (Landgericht) is to be considered about participation of persons with symptoms of cyclophrenia, esp. mania-[5f].
3. Catastrophic psycho-pathological situation in RH-Munich, similar to 1.&2. is given in media-[5a].
4. Administrator (female) from AG-M tried to manipulate a juridical-office, suggesting that AG-M should not recognize medical-attests [5c].

CONCLUSION. Juridical situation in Germany demonstrates - ignoring of moral philosophy, related to human obligations/I. Kant-[1] - contradiction to human-rights (EU-CHARTA, art.1-8/25-26/33-35) also to experimental ethics/Ch. Luetge et-al.-[6] and moral of personnel/R. Pegoraro-[7]. Ref. 1-7 and tables will be given to the presentation after acceptance (or email eva.neu@hotmail.de).

Only paradigm change in law-policy incl. enlarged implication of moral philosophy-theology, psychiatry-psychology, social philosophy in juridical eduction&practices could counteract disastrous juridical situation in Germany and on global level, supporting UNO-AGENDA21 for better education-health-ecology-economy (Table;see 2.).

(116) Title: On Psychiatry and Psychology in Context of Medical Philosophy in Times of Corona Pandemic

Authors: Michael Ch. Michailov1, Eva Neu1, Selma Krammer1,2, Daniele Gibault-Martin1,2, Roger Oswald1, Stephen Molnar1,3, Heike Wankel1, Erich Gornik1,4, Gero Hohlbrugger1,5, Helmut Madersbacher1,6, Germain Weber1,7 1 Inst. Umweltmedizin (IUM) c/o ICSD/IAS e.V. POB 340316, 80100 Muenchen, Germany (Int. Council Sci.Develop./Int.Acad.Sci. Berlin-Innsbruck-Muenchen-NewDelhi-Paris-Sofia-Vienna) 2 IUM Sektion Paris, France 3 IUM Sektion London,United Kingdom 4 Fac. Physics, Techn. Univ. Vienna, Austria 5 Med. Univ., Innsbruck, Austria 6 Klinikum Innsbruck (Dir.a.D.), Innsbruck, Austria 7 Univ. Luxemburg&Vienna, Fac. Psychology, Prof. Dr. (Dean), Austria

Abstract:

Introduction: Psychology and psychiatry are fundamental interdisciplinary sciences with essential importance for enormous health-problems of humanity. Creation of integrative Psychology and psychiatry in context of multi-dimensional&holistic medicine, founded by HIPPOCRATES-GALENUS-HUA T'UA-AVICENA-PARACELSUS is necessary to counteract disastrous human health-situation. Psychology and psychiatry needs new integrative therapy-models considering application of psychopharmacotherapy as well as practices of psycho-somatic (Th.v.UEXKÜLL) and somato-psychic theories (Y.IKEMI). Emperor AKIHITO during Opening-Ceremony of ICPM-2005-Kobe appointed to consider "total symptoms of mind-body, seeking ways of holistic care". This is of immense importance in time of corona pandemic. Implication of medical philosophy, esp. medical ethics in education&research in the fields of psychology&psychiatry is essential factor for future medical science.

Methods: Evaluation of psychic-"polar-attitude-list"/physiological-parameters: heart-rate, blood-pressure,etc. from patients/probands after training by occidental/oriental practices (Music-/Yogatherapy/ others) (ref.).

Results: Observations demonstrate strong positive influence after music[1], respiratory[2], hatha-yoga[3] therapies. Items of psycho-physiological (relaxed), emotional (tranquil/happy), cognitive (few/ordered thoughts), voluntary (active/spontaneous), social (open/assertive), consciousness (clear/sleepy) categories are significantly positive changed 25-50%. The 3- therapies have specific psychic-effects, e.g. items "relaxed/tranquil" after respiratory- (+45/50%) and music- (+20/5%), also item "open" after music-therapy (+25%) are positive, but negative after respiratory-therapy (-20%). Psychic-effects are correlated with positive physiological-ones,e.g. heart/respiratory-frequency decreased 25-30%, voluntary-apnoea prolonged 55%. Mountain altitude (>2000-3000m), hypothermia (<20 to 0°C) influenced positively psychic/ physiological-parameters, e.g. heart-rate/blood-pressure decrease (n=125, P<0.05-0.01) (Fig. 1-3).

Conclusion: Medical philosophy, esp. ethics is necessary for consideration of different methods from an integrative psychotherapy giving preference, e.g. for depression with suitable respiratory/physical-training, also hypothermia&high-mountain therapy (activation-euphoria), for mania:music-therapy (inhibitory-effect). Systematically research about single/combined therapies is necessary,e.g. for epilepsy: Respiratory-therapy/hypothermia,etc. could help patients (hypo-/hypercapnia: inhibitory/excitatory effects on CNS-structures). This way will be supported UNO-AGENDA21 for better education-health-ecology-economy on global level with special importance for corona pandemic time (ref. and tables will be given to the presentation, if accepted or eva.neu@hotmail.de).

(117) Title: On Resident Houses: Example with Psychopathology of German Justice during COVID-19 Pandemic

Authors: E. Neu1, M.Ch. Michailov1, Manfred Holler1,2, Renate Neu1, Peter Birkenbihl1, Marie-Luise Gräfin Brockdorf1, Gero Hohlbrugger1,3, Alfons Hofstetter1,4, Helmut Madersbacher1,5, Ernst Rainer Weissenbacher1,6 1 Inst. Umweltmedizin (IUM) c/o ICSD/IAS e.V. POB 340316, 80100 Muenchen, Germany (Int. Council Sci.Develop./Int.Acad.Sci. Berlin-Innsbruck-Muenchen-NewDelhi-Paris-Sofia-Vienna) 2 Univ. Hamburg, Fac. Economics, Prof. Dr. (Dean), Hamburg, Germany 3 Med. Univ., Innsbruck, Austria 4 Klinikum Grosshadern (Dir.a.D.), Univ. Muenchen, Muenchen, Germany 5 Klinikum Innsbruck (Dir.a.D.), Innsbruck, Austria 6 Dept. Gyn., Klin. Grosshadern, Univ. & Practice Premium Med., Muenchen, Germany

Abstract:

Introduction: Social PSYCHOPATHOLOGY is essential for solutions of enormous resident-house/RH-conflicts, esp. in Germany, leading to immense psychic&medical problems-[2a-e,3]. Millions tenants in Europe: Germany-54.3%/Austria-30.2%/France-25.3%/GB-24.1%/Italy-12.9%/Slovenia-4.5%. German journals reflect catastrophic situation of tenant-lessor conflicts-[3]. Application of psychosomatics&psychiatry could counteract RH-psychopathology. During Opening-Ceremony of 18thWorld-Congress Psychosomatic-Medicine (ICPM 2005 Kobe) were present their majesties Emperor&Empress of Japan, Ministers. Emperor AKIHITO honoured congress by strategical ideas, "total symptoms of mind&body, seeking ways of holistic care … it is extremely important for patients ... my hope contributes ... the progress of medical science and people's

happiness in the entire world". Yujiro IKEMI/ICPM-President opened new-dimension in medicine&psychology by somatopsychic theory&self-regulation practises (Yoga/Qigong/Zen-meditation/etc.) with occidental psychosomatics (Th.von UEXKÜLL).
Methods: Psychological-medical-social observations-[2a,e].
Results: Complex interaction of social-natural factors (micro-ecology/apartments) are demonstrated by conflicts tenants-lessors (RH-Munich). Conflicts conc. high-rents, luxurious repair, cause dangerous psycho-neurological diseases: anxiety-neurosis-insomnia-depression,etc., esp. in patients/seniors with cardio-vascular pathology. Defect-doors&radiators&windows (air-currents) induce respiratory-diseases, defect-illumination causes accidents (neuro-orthopaedic diseases: commotio-cerebri,etc.). Examples for impossible situation in German-RH: After 47years annihilation of RH-contract (tenant-woman 74years); over 5years lessor tries to eliminate 2scientists from RH, living-working over 45/55years (one invalid-68, other-88years, both with complex pathology) by justice-terror; RH-contracts of tenants 90years with dementia&blind-senior (90years) are annihilated! RH-conflict leads to lethal consequences of 73year tenant-[3].
Conclusion: Implication of medical philosophy,esp. ethics, psychosomatics could help millions of tenants injured by RH-conflicts-[2a-c,1a,b] by (a)-psychotherapy&education-[2d], (b)-education of RH-administrators incl. philosophical/psychological/psychiatric-examination, (c)-foundation of "house-councils" for "RH-industry" counteracting psychopathological/-somatic diseases. It will be discussed new approaches to moral philosophy and theology related to human obligations acc. to I.KANT. Over 200years ago he differentiated physiological&pragmatic anthropology. This concept was enlarged by conception about an integral anthropology given in reports to philosophical-psychological-medical congresses and giving recommendations for UNESCO-WHO-EU-governments in pandemic times. This way will be supported UNO-Agenda21 for better health/education/ecology on global-level (Table, ref.1,2,3 will be given to the presentation after acceptance (or email eva.neu@hotmail.de)).
DEDICATION for support by Profs.: Austria: E.Busek, E.Gornik, K.Lorenz*, France: J.-M.Lehn*, J.Dausset*, Germany: J.Deisenhofer*, K.v.Klitzing*, H.Michel*, E.Neher*, W.Scheel, J.&Th.v.Uexküll, B.Vogel, GB: Sir A.Hewish*, B.Josephson*, Sir J.Kendrew*, N.Tinbergen*, Lord A.Todd*, India-USA: G.Govil, H.G.Khorana*, L.Pauling*, B.Skinner, K.Singh, Japan-USA: L.Esaki*, K.Fukui*, Y.Ikemi, S.Tonegawa*, T.Sugahara (*Nobel- Laureate)

(118) Title: On Medical Ethics And Policy in Pandemic Times

Authors: Eva Neu1, Michael Ch. Michailov1, Heidrun Schmitz1, Nicoletta Moro1,2, Ursula Welscher1, Tatjana Senn1,2, Boleslav Lichterman1,3, Sergej Kuznetsov1,4, Dieter G. Weiss1,5, Germain Weber1,6 1 Pharmaco-Physiology, Inst. Umweltmedizin (IUM) c/oICSD/IAS e.V., POB 340316, 80100 M. (Int.Council Sci.Develop./Int.Acad.Sci. Berlin-Innsbruck-Muenchen-NewDelhi-Paris-Sofia-Vienna), Muenchen, Germany, 2 IUM Section Innsbruck, Austria 3 Russian Postgrad. Med. Acad., Moscow, Russia 4 Univ. Rostock (Prof.) Inst. Zellphysiol., Germany & Lomonssov Univ., Moscow, Russia 5 Univ. Rostock, Inst. Physiology (Dir.a.D.), Rostock, Germany 6 Univ. Luxemburg&Vienna, Fac. Psychology, Prof. Dr. (Dean), Austria

Abstract:
Introduction: Medical ethics is fundamental disciplic for the future, related to PHILOSOPHY (regina scientiarum/Immanuel KANT), MEDICINE, PSYCHOLOGY, BIOLOGY, which could initiate paradigmatic change beginning with scientific-policy.
Foundation of an INTERNATIONAL ACADEMY FOR MEDICAL ETHICS (IAME) with new aims&organization better than e.g. European Acad. Neurology (EAN, founded 2015 in Berlin) or Intern. Acad. for Pathology (IAP, founded 1906) could be example for the future, esp in pandemic time
Methods: Philosophical incl. ethical, psychological, medical consideration. Ref. and tables will be given to the presentation, if accepted or eva.neu@hotmail.de.
Results: CONCEPTION for discussion: IAME could include institutes for medical ethics as well as selected clinics for psychiatry (universities/others) via network of national-ones from selected countries as models for application of medical ethics for future education&research&practice in medicine and other health disciplines (sport, etc.). PRINCIPLES of IAME

1. New kind of organization,e.g. 3 honorary (permanent), 3 (fixed term) presidents/directors (meritocratic&triumvirate-principles).
2. Spiritual fundamentals: Education&research in philosophy as well as theology, e.g. Brahmanism-Yoga, Buddhism-Zen, Christianism-Mosaism, Confucianism-Taoism, Mohammedanism-Sufism, others.
3. Promotion of social responsibility-interdisciplinary-international co-operation.
4. Education in an theoretical and practical integral anthropology, i.e. general (philosophical/normative, pedagogic/educative, medical/curative-prophylactic as well as special anthropology), i.e. individual-spiritual-mental, etc. natural special anthropology (influence of factors), social-family-school, work, etc.
5. Possibility for whole life working for seniors: Honorary Presidents, directors, professors, etc. (permanent), usual functionaries: presidents, directors, etc. (fixed term.
6. Possibifor whole-life education acc. to Im. KANT, e.g. half day working and half day education
7. Continuation of education in philosophy-psychology-informatics.

Conclusions: It is to be considered physiological and pragmatic anthropology from I. KANT as well as philosophical, psychological, biological anthropology (Book ed. by Gamaer and Vogler) (ref). Scientific, political, financial support for foundation of IAME could help for realization of UNO-Agenda21 for better health-education-ecology-economy on global-level protecting self-destruction of humanity by misuse of discoveries. EACME and IUM could co-ordinate this global project with special importance for pandemic times.

(119) Title: Healthcare during pandemic in Europe: moral duty or deontological requirement?

Authors: Pietro Redaelli 1, Matteo Luca Burlando 1, Elia Manfrin 1, Chiara Rossetti 2; 1 Resident in Legal Medicine, Centre for Clinical Ethics Insubria University, Varese, Italy, 2 PhD student, Centre for Clinical Ethics Insubria University, Varese, Italy

Abstract:
The Code of Medical Ethics describes the standards of conduct of the medical profession, but at the same time reflects the principles of medical ethics and cultural traditions of each country. In this work we developed a comparative analysis of the ethical codes of different European countries regarding the subject of doctor's duties during situations of public need: natural disasters and pandemic events such as the recent Covid-19 emergency.
We underlined the similarities and differences between the different Codes, highlighting how the obligations for the healthcare professional are much more taxing in some countries, while in other European states

the Deontology Code restricts to briefly mention this issue in a single short article.
According to an European viewpoint, we focused on the European Charter of Medical Ethics adopted in Kos in 2011 and we underlined the limits of the project of a common European Code of Medical Ethics showing the complexity of harmonising national ethical rules. At the same time a common European Code can be a practical instrument to safeguard patient's needs and to guide doctors' medical practice in an European context.

(120) Title: Ethics of Infectious Diseases: A systematic Review of Emerging Topics

Authors: Elda Righi 1, Massimo Mirandola 1, Michael John Dwyer2, Alessandra Agnese Grossi 3;1 Infectious Diseases, University of Verona, Italy; 2 NEXS, University of Copenhagen, Denmark & Department of Human Sciences, University of Verona, Italy, 3 Center for Clinical Ethics, University of Insubria, Varese, Italy.

Abstract:
Background. The broad field of infectious diseases ethics (IDE) encompasses several global challenges deriving from the unpredictable, explosive, and global impact of emerging infectious diseases (ID), including stigmatisation, limitations of privacy, and liberty to promote the public good. We performed a systematic review on the emerging IDE topics during the past 3 years.
Methods. This study was conducted in accordance with the PRISMA guidelines. We searched the Medline databases from January 1st, 2019 to December 31st, 2021 for any type of publication in English, Spanish, or French language reporting IDE and including the principles of biomedical ethics ("justice", "autonomy", "beneficence", "non-maleficence"). Articles that did not refer to ethical issues but only to good clinical practice or infection epidemiology were excluded.
Results. A total of 139 articles (65% cohort studies and reviews) were included in the final analysis (17% from 2019, 45% from 2020, 39% from 2021). COVID-19 (33%) and HIV infection (27%) were the most reported ID, with COVID-19 reaching 46% of studies in 2021. The articles retrieved were mainly from high-income countries according to the WHO classification (81%) with most common areas represented by North America (47%), Europe (24%), and Western Pacific (13%). Only a minority were conducted in paediatric (13%) and female (9%) populations. The most frequent clinical-related ethics topics were equitable access to care and medical practice (37%). IDE themes included equity (59%), liberty (50%), discrimination (37%), greater good (33%), priority (26%), and privacy (13%). The most frequently addressed ethical principle in IDE was autonomy (62%), followed by justice (54%), non-maleficence (42%), and beneficence (39%). Compared to COVID-19, HIV-related studies showed a significantly higher proportion of ethical themes and principles related to liberty ($p=0.02$), autonomy ($p=0.007$), and privacy ($p=0.04$) and lower proportion of those referring to greater good ($p<0.001$), priority ($p=0.02$), and justice ($p=0.001$).
Conclusions. Newly emerging IDs were more commonly studied from an ethical point of view compared to other IDs. The most recent pandemics (HIV/AIDS and COVID-19) have been gaining attention from an ethical viewpoint. Key populations and low-to-middle income countries appear underrepresented, and ethical principles were unevenly distributed across diseases, highlighting key gaps in IDE.

(121) Title: Care for unvaccinated CoViD-19 patients: ethical issues

Authors: Mario Picozzi 1, Antonio Rimedio 2, Mario Eandi 3; 1 Associate Professor of Forensic Medicine, Insubria University, Varese, Italy - Director, Center for Clinical Ethics, Insubria University, Varese, Italy, 2 Center for Clinical Ethics – CREC, Insubria University, Varese, Italy - Ethics Committee of the University Hospital "Maggiore Della Carità", Novara, Italy - Regional Conference for Clinical Trials of the Piedmont Region, Italy, 3 President of Regional Conference for Clinical Trials of the Piedmont Region, Italy.

Abstract:
In the winter of 2021-22, the 'pandemic of the unvaccinated' presented new challenges to bioethics, because no-vax ideologies burst into hospital wards and doctors' offices, instilling mistrust in the care relationship and in some cases leading to the renunciation of life support. The same clinicians have called for different equity in the distribution of scarce resources during pandemic peaks because once again the needs of patients with other diseases have been subordinated to those of CoViD-19 patients non-vaccinated 'by choice'. However, careful consideration of bioethics leads to the exclusion that vaccination choice understood as social merit/demerit, should be included among the criteria for prioritizing treatment. It is contrary to the principle of beneficence to postpone the treatment of patients with CoViD-19 suffering from severe respiratory distress, to give priority to other patients who don't need urgent intervention. This would plan the death of those patients. The unvaccinated citizens have not violated, nor have they intended to violate, the principle of social reciprocity in such an irrevocable way to be worthy of death, which they would face if they were not rescued soon. Personal responsibility in refusing vaccination cannot be regarded as a 'waiver' of treatment in the event of an acute illness, let alone as a lesser right to treatment. We would find ourselves establishing a ranking of merit among the patients and the moment of treatment would turn into a sort of 'reckoning' to target behaviors understood as antisocial. Respect for the person and human dignity leads us to see in patients a value that far exceeds their wrong choices, even in the worst cases. We don't exclude exceptions in changing the priority criteria, where the risks to unvaccinated patients are greater than the expected benefits. Rather than remaining tied to the prospect of a painful competition between the rights of patients with different diseases, attention should be focused on the social reasons for the phenomenon of vaccine hesitancy and the plan for investment in healthcare.

(122) Title: Bioethics and clinical ethics paths for the future citizens: CREC's experiences

Authors: Silvia Siano 1, Elena Ferioli 1, Antonella Rudi 2, Dr. Giuseppe Lombardo 2, Mario Picozzi 1; 1 Center for Clinical Ethics, University of Insubria, Varese, Italy, 2 Liceo Scienze Umane "A. Manzoni", Varese, Italy

Abstract:
Starting from s.y. 2019/20, the Research Center of Clinical Ethics of Insubria University has launched an innovative project at the Liceo delle Scienze Umane "A. Manzoni" in Varese as part of Citizenship and Constitution education.
It involves the current third, fourth and fifth classes of the biomedical-health section of the Institute in a three-year course. It aims to implement educational paths in bioethics and clinical ethics for the education of the future citizens.
The general pedagogical intent that guides the construction of the above-mentioned itineraries is therefore the education to bioethical citizenship,

to be understood as active and responsible participation in bioethical choices, starting from the awareness of new rights and new duties related to scientific development. To do this, there is a need to link education in bioethics to the development of critical judgment, argumentation, active participation in the debate in a pluralistic ethical context. The formal presentation of the path of bioethics and related issues is treated directly by the experts of the Research Center of Clinical Ethics, through the definition of a conceptual framework of reference and the preparation of situations-problems, in the logic of the Project Based Learning model, which serve as a stimulus to arouse curiosity and interest of students and the consequent desire to approach the ethical reasoning to deepen the reasons to support less than a possible ethical decision. The problem situations selected by the experts come directly from the world of biomedicine and health care and are the basis for the first clinical case studies: in this way, students are asked to exercise their ability to argue and support the possible ethical positions thanks to the support of what was learned in the general study offered by the experts.
The feedback from the students, following the activities presented and carried out, also valid for their formative assessment, Paths for Transversal Skills and Orientation, is currently very positive: students have enjoyed and benefited from the collaborative methodology proposed and adopted, proving motivated and eager to critically rework what they learned to build a common product that expresses the best bioethical positions supported.

(123) Title: End-of-life in Italian and European jurisprudence: opinions in comparison

Authors: Federica Vincenza Tiso 1, Sonia Bovino 1, Giuseppe Vacchiano 2; 1 University of Sannio, Italy, 2 Associate Professor, University of Sannio. Italy.

Abstract:
The end-of-life stimulates lacerating ethical and juridical reflections because it is extremely difficult to balance the protection of life with the respect for the dignity and the self-determination of every person.
The Italian Constitutional Court recognized suicide aid not punishable, in some particular cases, but It declared that from the right to life derives the duty of the State to protect the life of everybody and not the one, diametrically opposite, to recognize to the person the possibility of obtaining an aid to die from the State or from third persons.
The European Court of Human Rights, instead, gave everyone the right to decide how and when to die, and, moreover, in some cases, concerning children suffering from serious congenital diseases, authorized the interruption of life-sustaining treatments, because it considered this decision the best interest of children, despite the dissent expressed by their parents. In other words, the Court established the prevalence of the superior control of the Judges on the rights of the parents and their affectivity.
There is a profound divergence between Italian and European jurisprudence: The Italian Constitutional Court protects the life and will of the patient (subjective criterion), while, the European Court of Human Rights privileges the best interest of the patient (objective criterion). This position is in conflict with the real essence of medical science and, moreover, it does not respect the dignity of the person.
In our opinion, only in some particular cases it is possible to ensure the patient a free, autonomous and conscious choice, but it is also clear that the end of life cannot be a choice imposed by National or European Courts.

(124) Title: Euthanasia in Spain: experience of the first year of application

Authors: Núria Terribas, Director - Fundación Victor Grifols i Lucas, Member of the Commission for the Guarantee and Evaluation of Euthanasia in Catalonia

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 reviewed more than 130 applications in 1 year, of which about 70 have been approved, others have been denied and in others the patient died before finishing the process. After a year of application, the situation is very diverse in the different territories of Spain so that some Autonomous Governments have barely received and resolved the first applications. 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. To date there is no annual report of the entire Spanish territory that collects the global figures. Also, in this first year, difficulties have appeared in interpreting the law according to the cases (interpretation of suffering in mental health, chronicity and old age, etc.) that we are trying to solve case by case.

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Saturday, September 17th, 2022
Plenary Session 4: The dialogue towards the future: new and emerging technologies

Chair: Giovanni Bernardini – Round Table: Davide Battisti (University of Insubria, Varese) Marianne Boenink (Radboud University Medical Center, Nijmegen) Massimo Reichlin (Vita-Salute San Raffaele University, Milan)



Davide Battisti is a research fellow at the Center for Clinical Ethics, University of Insubria and an adjunct professor of Bioethics at the University of Milan/Vita-Salute San Raffaele University. He also is co-director of the fall school "Bioethics in "Society, promoted by the Center for Clinical Ethics and the Lake Como School of Advanced Studies. He recently earned with honours his PhD in Clinical and Experimental Medicine and Medical Humanities at the University of Insubria (Como – Varese, IT), with a thesis titled "Redefining Procreative Responsibility in the field of the Continuous Development of Assisted Reproductive Technologies". He spent a research period at The Interfaculty Centre of Biomedical Ethics and Law (KU Leuven, BE) and was a "Recognised PhD student" at the Oxford Uehiro Centre, University of Oxford (UK). Davide Battisti wrote papers and commentaries on international journals such as Bioethics, American Journal of Bioethics Neuroscience, Social Epistemology, Phenomenology and Mind, etc. His paper "Genetic enhancement and the child's right to an open future" was awarded as the best-published paper by the Italian Society of Moral Philosophy. His research interests are ethics of genetics, genome editing, reproductive ethics, enhancement; bioethics, science communication.

Abstract:

Assisted reproductive technologies are often conceived as tools that increase our procreative freedom. Nowadays, thanks to In Vitro Fertilization (IVF), Preimplantation Genetic Diagnosis (PGD), and prenatal testing among others, prospective parents have a wide range of reproductive choices available. Alongside this line of thought, some bioethicists argue that the aforementioned reproductive techniques also raise unprecedented moral obligations towards progeny and a balance between procreative autonomy and responsibility is needed. Accordingly, some models have been proposed such as the Child's Right to an Open Future and the Principle of Procreative Beneficence. Stemming from a consequentialist person-affecting perspective, I first argue that these models cannot be accepted. We should instead embrace the least demanding Minimal Threshold Model (MTM), according to which every reproductive choice is permissible, except for creating children whose lives will not be worth living. Then I argue that whereas MTM is plausible in a context in which only selective reproductive technologies are available, things can change if we consider the future and still hypothetical availability of reproductive Genome Editing (rGE). After claiming that rGE can be considered a person-affecting technique, I argue that prospective parents have a greater moral obligation toward their progeny than in a context in which only selective technologies

are available such as a PGD. I then investigate when parents-to-be face this new moral obligation by proposing two models: the Bold Restriction of Procreative Freedom and the Mild Restriction of Procreative Freedom. According to the former, every reproducer has a prima facie moral obligation to procreate through IVF and then transfer into the uterus an embryo free from genetic diseases that, although compatible with a life worth living, significantly harm the future child and for which, at the moment of the procreative decision, safe treatment with rGE to avoid this condition is available. I argue that this model is too demanding and difficult to defend from a consequentialist person-affecting perspective. Therefore, I present and defend the Mild Restriction of Procreative Freedom, arguing that the aforementioned prima facie moral obligations apply only to prospective parents who are already in the IVF process.



Marianne Boenink is professor in Ethics of Healthcare at the Radboud University Medical Centre in Nijmegen, the Netherlands. She studied Health Sciences (Maastricht University) and Philosophy (University of Amsterdam), combining the two since she started working as a postdoctoral researcher in the domain of philosophy and ethics of biomedical technology at the University of Twente. In her current position she teaches a variety of ethics courses in medicine and biomedical sciences programs. Her research focuses on philosophical and ethical challenges related to emerging biomedical technologies, with a particular interest in visions and practices of data-intensive healthcare. Moreover, she acts as an ethical advisor for research ethics committees, the Dutch Commission on Genetic Modification, as well as multiple international research consortia. Marianne has led several multidisciplinary research projects investigating conditions for responsible innovation, publishing about, among other things, innovations in Alzheimer diagnostics and in prognostication of patients in coma after cardiac arrest. She also developed tools to facilitate early deliberation on the desirability of emerging technologies. Ultimately, her aim is to put ethical questions on the agenda early on during technology development, to facilitate ethical deliberation among stakeholders, and thus to contribute to good healthcare innovation.

Abstract:

Current imaginaries of the future of healthcare put *data* center stage. Collecting, connecting and analysing data is expected to bring about 'data-driven' or 'data-intensive healthcare'. This is supposed to enable more precise and more effective treatments, as well as improved prediction and prevention. Although much might be gained



from data-intensive healthcare, there are also quite a few ethical concerns. In my contribution I first give an overview of the various ethical challenges put forward in the literature. I then take the opportunity to point at some issues that I think have been insufficiently highlighted thus far, and finally share some thoughts on the type of ethics that might be needed to address these issues.

Ethical issues of data-intensive healthcare can be related to (1) data collection, storage and access (challenging, among others, autonomy and privacy), (2) data analysis (possibly challenging safety, fairness and transparency) and (3) data use (raising concerns about solidarity, responsibility or trustworthiness, among others). Such challenges repeatedly force us to ask whether and how human understanding and control can sufficiently address the complex and dynamic system character of data-driven healthcare.

Whereas the current ethical literature on data-driven healthcare identifies numerous values that might be challenged, the question whether and how it impacts the value of *health* is hardly addressed. I argue that this may be related to the ethical tendency to solve ethical issues by balancing intended benefits with potential drawbacks. However, we should not take for granted that data-driven healthcare will produce more health. The increasing 'datification' of health may actually shift the meaning of 'health', and therefore also the goals and boundaries of healthcare.

I conclude that we not only need novel strategies to address ethical issues in a dynamic and complex system, but that we should also engage in hermeneutical analysis of possible changes in the meaning of 'health'.



Massimo Reichlin is Full Professor of Moral Philosophy at the Faculty of Philosophy, Vita-Salute San Raffaele University in Milan. He graduated in Philosophy at the Catholic University of Milan and received his Ph.D. in Bioethics at the University of Genoa. He has taught Bioethics, Contemporary ethics and History of Moral Philosophy both at the San Raffaele Faculty of Philosophy and at several other academic institutions, including the University of Bergamo, the Humanitas University at Milan, the Theological Faculty of Northern Italy and the University of Milan (in a joint MA program with San Raffaele University). He served for twenty years in the Ethics Committee of the Scientific Institute San Raffaele. He was a founding member of the Italian Society for Neuroethics (SINe), of which he has been Vice-President from 2014 to 2021. He has published books and articles concerning bioethical issues such as euthanasia, abortion, the vegetative state and biomedical enhancement, as well as on topics in contemporary ethics and the history of moral philosophy, such as deontological approaches to normative ethics, moral conscience, utilitarianism, and moral intuitionism.

Abstract:

A wealth of recent, non-invasive studies of the human brain have created a new, brain-centered anthropology. New knowledge and a previously unknown capacity to manipulate the human brain have led to a stark contrast between the naturalized 'scientific image' of human beings and the 'manifest image' of them which is still reflected in folk psychology. Such opportunities to manipulate the brain, either for therapeutic or enhancement purposes, have led to a new domain of research called neuroethics. This is generally divided into two sections: the 'ethics of neuroscience' section can perhaps be thought of as a subsection of bioethics, dealing with respect for human persons in neuroscientific research, whereas the 'neuroscience of ethics' section can best be conceived as a sort of scientifically-informed discussion of theoretical issues in moral philosophy, such as the nature of moral judgment and the existence of free will. The main concern is that the most popular neuroethical accounts offer a picture of human beings that casts doubt on some of bioethics' most cheered values, such as autonomy, and that seems to entirely jettison basic philosophical concepts, such as that of free will, or the idea that moral judgment involves the reflective weighing of reasons. Several novelties can be expected to arise from the domain of neuroscience in the coming decades; the dialogue of medical ethics with these developments is inevitable and important; but the encounter with these recent developments may also bring us some bad news, and we must be prepared to question, or perhaps even to revise, some of our basic notions and principles.

Abstract Book

Parallel Sessions 4
Room: 1MTG
Chair: Maria Aluas

(125) Title: Decision-making authority and the child's best interest in end of life-decisions

Authors: Marianne K. Bahus, PhD, Department of Law, University of Agder

Abstract:
The best interests of the child shall be a fundamental consideration regarding life/death-decisions for seriously ill children according to the Convention on the Rights of the Child Article 3 no. 1 and the Norwegian Constitution Section 104. To assess what the notion "the child's best interests" regarding life/death-decisions imply, it must first be clarified which elements are to be included in the assessment of which alternative treatment is in the child's best interests, second how to harmonize factors that are in opposite directions, and third how to harmonize the child's best interest with other fundamental considerations. Furthermore, it must be clarified who will make the final decision if it is not possible for parents and health personnel to reach an agreed decision, or if the choice of treatment is not clear.
According to national legislation the child's parents shall supervise the child's autonomy, hereby consent to or deny treatment, and shall practice parental responsibility in accordance with the child's best interest. Conflicts between health personnel and parents may appear when the parents want life-prolonging treatment while health personnel want palliative care for the child, or the opposite. Another challenging situation appears when there is medical and ethical uncertainty whether a child should have life prolonging treatment or palliative care.
The Committee on the Rights of Children has in General Comment no. 14, "The right of the child to have his or her best interest taken as a primary consideration", given some general guidelines on the content of the principle of the child's best interest. The Norwegian Directorate of Health has worked out guidelines regarding end of life-decisions, but they do not elaborate on the content of the child's best interest.
I will analyse different elements that may be included in the assessment of the child's best interest regarding end-of-life decisions involving children. I will also analyse the legal situation, including who have the decision-making authority, when parents prefer life-prolonging treatment while health-personnel recommend palliative care or the opposite, and when the decision is medically and ethically uncertain.

(126) Title: The dialogue between doctors and patients – Barriers in respecting patients autonomy in Transylvania healthcare settings

Authors: Maria Rajka , Cristuru Secuiesc Healthcare Center, medical doctor. Maria Aluas, University of Medicine and Pharmacy Iuliu Hatieganu, Cluj-Napoca, Department of Oral Health, Associate Professor

Abstract:
Transylvania is a region in central Romania. Over the centuries, it has never been a homogeneous territory, in terms of population, language and customs, being an area inhabited by both Romanians and Hungarians, along with Germans, Roma, and several other ethnic populations. Although the education is compulsory until the first cycle of high school, 14 years (from the last year of the kindergarten to the twelfth grade), statistics on the educational level of the population in the area, especially among the Roma, show a high level of illiteracy (31%).
Thinking in terms of patient autonomy in an ideal way, we think of a capable person who wants to know the truth about his/her disease, competent to make decisions for himself/herself. In the current medical practice, we have situations when, the patient seems to be autonomous and entitled to self-determination legally speaking, in fact, he/she cannot really process the information we provide with. Such limitations are primarily the educational ones, elementary: the patient cannot read or write. In Transylvania, there are certain cities and regions where different communities, and ethnic minorities are living together. Most part of them do not speak, or they speak a basic Romanian, but they do not understand the official language. And all official documents for informing patients and the informed consent form in healthcare settings are provided in Romanian.
In this presentation we will highlight the educational, cultural and linguistic aspects that can create serious challenges for clinicians. In my work, I frequently have cases where the informed consent, even if it is made in a formal way, it does not represent a real partnership between doctor and patient.
The purpose of the presentation is to highlight the ethical issues faced by a clinician in Romania, illustrated by clinical cases.
"To be fair, in the ethical sense of the term, is not to confine oneself to respecting the law", but "treating fellows as beings who are not identical" (Pierre le Coz).

(127) Title: Aesthetic Dentistry put at Risk the Dental Profession: Millennials and Generation Z perspectives

Authors: Stud. Bianca Georgiu 1 , Assoc. Prof. Maria Aluaş PhD 1 , Assoc. Prof. Rouven Porz PhD 2; 1. Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania; 2. University Hospital of Bern, Inselspital

Abstract:
Social media (SM) have a huge impact on young generations' way to communicate with each other, transmit messages, and promote activities. SM is used predominantly by two particular generations: the Millennials and Generation Z. These generations have distinctive characteristics when it comes to interacting with SM platforms. The Millennials are people born from 1981 to 1996 and they are the first generation that grew up in the Internet age. Generation Z (or Gen Z), also known as zoomers, are people born in the mid-to-late 1990s (…) and the early 2010s. Dental professionals are using nowadays social media platforms to promote the medical acts and to attract new patients. They sometimes offer free treatments or important discount especial for esthetic procedures. Our main ethical concern is the risk to deviate a medical profession to profit-oriented businesses.
The study's purpose was to explore the perceptions of Millennials and Generation Z dental professionals toward the use of social media to promote aestetic dentistry and identify the ethical issues related to this practice.The specific aims were: a) to identify conflits of interest on using social media in promoting esthetic dentistry; b) to highlight difficulties on truth telling to patients about the actual medical condition, if necessary; c) to explore participants perception on the duty to preserve patient good instead economical gains or viceversa.
In conclusion, we will indicate relevant changes in doctor-patient relationship and the risk of changing the nature of medical profession.

(128) Title: Ethical access to non-reimbursed anti-cancer treatments: an interview study regarding the moral views of Dutch hospital directors and managers.

Authors: Charlotte H. C. Bomhof (MSc, PhD candidate), Eline M. Bunnik (PhD, associate professor), Erasmus Medical Center, Rotterdam, the Netherlands

Abstract:
Background: Anti-cancer treatments which have entered the market are not always immediately reimbursed through the basic healthcare package. If treatments are not yet reimbursed, hospital directors and managers are confronted with ethical dilemmas, for instance when to use hospital budgets to pay for non-reimbursed treatments or allow patients to pay for treatments out of pocket. Little is known about hospitals' policies regarding non-reimbursed treatments. This study examines the experiences and moral views of hospital directors and managers regarding access to non-reimbursed treatments.
Methods: Interviews were carried out with hospital directors, hospital board members and hospital heads of departments in the Netherlands (N=17), and thematically analyzed.
Results: Respondents expressed concerns regarding the rising costs of cancer treatments and the affordability of the healthcare system. While in some hospitals, treatments were occasionally paid for using hospital budgets, in other hospitals, this did not occur. In some hospitals, non-reimbursed treatments were not prescribed if they were not recommended in clinical guidelines, while in other hospitals, respondents actively helped physicians with looking for other ways of offering access to non-reimbursed treatments. In general hospitals, patients were often referred to academic hospitals if a relevant treatment was not yet reimbursed. Respondents differed in their moral views on information provision to patients regarding non-reimbursed treatments.
Conclusion: Practices and policies for providing access to non-reimbursed anti-cancer treatments vary amongst hospitals in the Netherlands. Consequently, this might lead to unequal access to non-reimbursed anti-cancer treatments among Dutch patients, based on the hospitals in which they are treated.
Key words: Medical ethics, anti-cancer treatments, funding and reimbursement, access, interview study

(129) Title: The Controlled Donation After Circulatory Death in France: a clinical ethics exploratory study

Authors: Milena Maglio, PhD, Centre d'éthique clinique AP-HP

Abstract:
In 1968, the Ad Hoc Committee of the Harvard Medical School identified brain death as the definition of death of the human being. There were two main reasons for this new definition: the first was the withdrawal of life-sustaining treatment (notably artificial respiration) in patients whose the brain was irreversibly damaged, and the second was the possibility to obtain from them organs for transplantation.
More than 50 years later, the definition of death remains controversial in the bioethics literature. Controlled donation after circulatory death has contributed to increased criticisms of the definition of brain death and the dead donor rule.
In France, controlled donation after circulatory death has been authorized since 2014 in some centers. In 2021, 44 centers were authorized and controlled donation after circulatory death increased by 43,7% compared to the previous year and represented 10,5% of total organ procurement activity. This practice is therefore currently considered a crucial source of organs. Despite these results, it raises important ethical concerns and questions for clinical practice.
In 2019, the Paris Clinical Ethics Center launched an exploratory clinical ethics study on the topic to better understand, from the perspective of healthcare professionals, their ethical arguments relating to this practice. 42 professionals with different experiences and opinions on this practice were included in the study.
This intervention aims to present their main ethical issues. We found that bioethical literature and clinical practice differ in the identification of ethical issues. Rarely does this practice question the dead donor rule or the definition of death. Their ethical issues are closer to their end-of-life decisions and practices. Controlled donation after circulatory death becomes an indicator of existing problems about end-on-life decisions and practices and may exacerbate them or, with the experience, improve them. End-of-life practices and the possibility of donation are in constant tension. It is therefore necessary to find some kind of balance between end-of-life practices and the possibility of organ procurement. Certain medical strategies make it possible to maintain this balance or to face certain fears that are based in a phantasmic way in the background of this practice. In this respect, the concept of "structuring fiction" seems useful.

Parallel Sessions 4
Room: 2MTG
Chair: Katarzyna Bielinska-Kowalewska

(130) Title: Deception by design: a systematic review of normative guidelines on deceiving research participants

Authors: Kamiel Verbeke, MD, PhD-student (1) & Tomasz Krawczyk, MA (2), Prof. Dr. Dieter Baeyens (3, 4), Dr. Jan Piasecki (2), Prof. Dr. Pascal Borry (1). // Institutions: (1). Center for Biomedical Ethics and Law, Faculty of Medicine, University of Leuven, Belgium; (2). Department of Philosophy and Bioethics, Faculty of Health Sciences, Jagiellonian University Medical College; (3). Chair of Social and Societal Ethics Committee, University of Leuven, Belgium; (4). Research Unit Parenting and Special Education, Faculty of Psychology and Educational Sciences, University of Leuven, Belgium

Abstract:
Participants are frequently deceived in research. This research method presents itself under many guises, think about the use of a cover story or withholding critical information. It occurs in a wide variety of fields, ranging from the biomedical sciences over computer science and robotics to the social sciences. As seems suitable for such a pervasive methodology, it has been at the center of widespread debate in the research ethics literature, where most of the attention has gone to issues such as informed consent, debriefing and trust in the research enterprise. Nevertheless, up till now there is no clear consensus on how to ethically deceive participants. Therefore, we set out to dissect current recommendations to determine common grounds and to make explicit the diverse perspectives on unresolved topics that need further debate.
The goal of our study is to chart how guidelines and position papers on research ethics address the use of deception. Hence, we performed a systematic review in which we analysed these guidelines looking for specific recommendations on deception. For this procedure, we set out to follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations for systematic reviews, and the adaptation for systematic reviews of normative guidelines. A collection of guidelines and position papers was established through (i) relevant lists of research ethics guidelines, (ii) searches in established databases and

grey literature, and (iii) snowballing through reference lists. Consequently, we looked into the conditions under which deception is deemed acceptable and compared recommendations regarding various issues, such as informed consent, debriefing, privacy-related safeguards, the use of non-deceptive alternatives, etc. Ultimately, through this study we aim to contribute to a better understanding on the areas of guideline convergence and divergence regarding the use of deception in research. And maybe, this can prove to be one of the much needed steps towards increasingly clear moral recommendations for those who aim to respectfully deceive participants.

(131) Title: Bridging the gap between theory and practice: developing translational bioethics

Authors: Dr Lucy Frith, Reader in Bioethics, Centre for Social Ethics & Policy, University of Manchester

Abstract:
The debate over translational bioethics has been growing in the literature since the early 2000s. This paper will take as its starting point the premise that developing translational bioethics is a worthwhile endeavour and explore what translation bioethics might look like, what counts as 'good' translational bioethics and what implications this would have for bioethics as a whole. I will argue that if we are to be serious about instituting translational bioethics, then it will need to look and be organised in a very different way from current bioethics research. My proposal here is not that translational bioethics should supplant existing ways of doing bioethics, but rather it will be an addition to it, another arm of bioethics. This will be a radically different form of bioethics from what we currently have and, in this paper, I will sketch what this might look like.
I will divide bioethics into two main types, academic focussed bioethics and practically focussed bioethics (including empirical ethics), arguing that they have different aims for their work and different criteria for quality. Translational bioethics, under my account, builds on research in academic and practically focussed bioethics, as translational biomedical research builds on and is related to 'basic' science. We can make an analogy between the translation pipeline of biomedical science, the trajectory of 'bench to bedside, and a bioethics translation pipeline. Transitional bioethics would operate at the end of the pipeline, where the products of research are implemented in practice, with translational bioethics main motivation being to affect change in the real-world. The paper will use the example of an empirical ethics project conducted on managing non-Covid services during the pandemic to illustrate these points.
The paper concludes by considering potential benefits and criticisms of this formulation of translational bioethics. Properly constituted, translational bioethics could be a valuable development for all forms of bioethics. It would both preserve theoretical work in academic bioethics, without forcing it to have impact, and enable the development of a form of bioethics that is specifically designed to have real-world impact.

(132) Title: Beyond a rhetoric of safety - where "CRISPR ethics" needs social epistemology: The case for philosophy of science in translational research ethics.

Authors: Katharina Trettenbach, Doctoral Candidate in Medical Ethics, University of Tübingen & University of Potsdam

Abstract:
The question of how to bring germline genome editing from the bench to the bedside, given societal approval, in the best possible "responsible pathway" has kept bioethicists, scientists, policy makers and many others around the globe thinking for the last couple of years.
Should societies indeed decide to bridge the way from bench to bedside for germline genome editing, established principles in research ethics (such as scientific validity, independent review, scientific and social value, a favourable risk-benefit ratio, fair subject selection, informed consent and respect for research participants) will have to apply, all the more so given that the stakes appear raised in comparison to somatic gene therapies: After all, germline genome editing, as a potentially heritable genetic alteration, could affect not only a single person, but multiple generations to come. The possibility for its hereditability and intergenerationality has germline genome editing pose additional challenges for research ethics, such as how to reconcile the interests of all affected parties (namely the prospective parents, their offspring and possibly their offspring´s descendants).
The principle of scientific validity holds a special place in research ethics in general and in this particular case of translational research ethics as its absence renders a discussion of the remaining principles moot and any further research into translational germline genome editing unethical. In my paper, I will show how and why a discourse that has often focused on the future "safety" of germline genome editing technologies, will need to direct its attention to the concept of scientific validity and how best to facilitate it in practice. I will also show how considerations of scientific validity in the context of germline genome editing have tended to focus on the validity of individual studies and experiments, but that in order to succeed in achieving the oft-demanded "safety" of germline genome editing, bioethicists, scientists and policymakers need to look beyond individual studies and take note of the social epistemology of science as well as input from philosophy of science more broadly as both can help to facilitate ethical translational research.

(133) Title: Data Sharing Platforms: Instruments to Inform and Shape Science Policy on Data Sharing?

Authors: Thijs Devriendt, Leuven, Belgium

Abstract:
Data sharing platforms are being constructed to make cohort data more findable, accessible, interoperable, and reusable. This is anticipated to enhance the sharing of data. However, the lack of data sharing has also been attributed to the lack of incentives for sharing. In this sense, a lack of data sharing has its roots in science policy. This includes, among others, the designs of attribution and reward systems, funding allocation mechanisms and data governance. We argue that data sharing platforms can aid in addressing policy barriers to data sharing. Platforms can be made into policy instruments that generate information on data sharing processes and the functionality of data access committees. This allows platforms to be used for various purposes. These include meta-research projects that inform policy development, observing effects of novel policies, the monitoring of data sharing practices, funding prioritization for cohorts and data infrastructures themselves and developing key performance indicators on data sharing. While platforms are just technical instruments, they are therefore still closely connected to policy evolutions in the context of open science.

(134) Title: Translational Bioethics: On what it can be, how it should work, and what efforts it will require

Authors: Kristine Bµrøe, PhD, University of Bergen

Abstract:
As pointed out by A. Cribb, just as 'translational research' in medicine requires researchers to identify steps to transfer basic scientific discoveries from laboratory benches to bedside decision-making, much bioethical research shares a similar aim of producing and transferring knowledge

from the desk to the practice. Theoretical research on normative issues concerns how the world should be, and this knowledge can be transferred to society in terms of improved institutions and the individual actions shaping medical practice. Translational ethics has been further developed as a distinct theoretical and methodological approach to bioethics, one that incorporates normative, empirical, and foundational ethics research. This approach takes as its starting point i) the epistemological and practical challenges involved in bridging the gap between the theoretical ethical work carried out by academic researchers, on the one side, and the empirical experiences, needs, capacities, motivations, and contextual circumstances in the field of everyday, ethical practice on the other; and ii) the view that academic endeavors are also constrained by contextual factors specifying the practice of doing academic work. These contextual factors, such as requirements for consistency and rigorousness and the academic ethical approaches they shape, do not represent an external source to the correction of human practice; the academic approach is itself a distinct part of human practice. This has implications for how to perceive the bridging activity between theory and practice. Indeed, it might challenge the role that experts on theoretical approaches to bioethics might have expected to have on 'controlling' a knowledge arena of the 'good' and 'right' of practice. Thus, there is an epistemic gap when it comes to 'ethical policy-making'; who should ultimately decide the bioethical content policies, how should acceptable policies be reached and what should be the specific ethical content of those polices?
In this presentation, I will develop my previous approach to translational (bio)ethics further by exploring how bioethicists can, and should, translate between the academic and practice field of ethics, while striving to ensure the 'ethics of bioethical approaches' in face of power constraints on both the academic practice itself and the policy-making processes.

Parallel Sessions 4
Room: 4MTG
Chair: Alessandra A. Grossi

(135) Title: Alcohol consumption in nursing homes. Experiences, moral visions and dilemmas of stakeholders.

Authors: Dr. Elleke Landeweer, University Medical Centre Groningen. The Netherlands

Abstract:
Background: Various residents of nursing homes enjoy drinking alcohol beverages. This regularly leads to moral questions and discussions addressing the scope and limits of autonomy. When would it be morally acceptable to limit alcohol consumption of nursing homes residents?
Aim of the study: Aim of this study was to develop insight into how residents and nursing home staff view alcohol consumption in nursing homes and to support nursing homes to deal with alcohol consumption in morally better ways.
Method: An explorative qualitative study has been done with the use of interviews with residents (4) and staff (14), as well as a mixed focus group with residents and staff.
Results: While residents viewed alcohol consumption as a private matter, moral visions of staff were not uniform. In practice, staff is often confronted with diverse moral questions that find its base in different values, circling around how to give meaning to values like respect for autonomy, quality of life, truthfulness and (collective) safety and how should be in the lead to uptake moral responsibility. Based on the outcomes a value scheme is developed that may support staff in pinpointing which values and norms are undermined in concrete situations.
Conclusions: Alcohol consumption in nursing homes raises a variety of moral questions in practice. This study advises staff to use the value scheme in case of concrete moral questions as a tool to careful analyse which values and norms are at stake as start for moral dialogue.

(136) Title: The dialogue in clinical practice: Scope and limits of autonomy in clinical practice

Authors: Kristiane M. Hansson, PhD research scolar, Centre for Medical Ethics, Institute of Health and Society, Faculty of Medicine, University of Oslo

Abstract:
Background: The uptake of family involvement in health care services for patients with psychotic disorders is poor, despite a clear evidence base, socio-economic and moral justifications, and guideline recommendations. To respond to this knowledge-practice gap, we conducted the cluster randomised controlled trial: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centres (IFIP). Among numerous barriers hampering the involvement of family members in treatment and decision-making processes, confidentiality issues constitute a major barrier. Nested in the IFIP trial, this sub-study aimed to explore what ethical challenges and barriers mental health professionals experience related to the duty of confidentiality in family involvement during the treatment of persons with psychotic disorders. We also explored what measures can improve the handling of such challenges.
Methods: We performed 21 semi-structured focus group interviews, including 75 participants in total. Implementation team members were interviewed at the initial and middle phases of the intervention period, while ordinary clinicians were interviewed in the late phase. A purposive sampling approach was used to recruit participants with various engagement in the implementation process. Data were analysed using manifest content analysis.
Preliminary results: We identified fourteen subthemes and four overarching themes that reflected the participants' experiences with confidentiality issues in family involvement. Two themes highlight barriers and ethical challenges: 1) Dealing with patient refusal 2) Lack of competence and legislation triggering moral distress. Two themes highlight measures to facilitate better handling of the duty of confidentiality: 1) Training in family involvement and confidentiality, followed by practice 2) Standardisation and routines.
Preliminary conclusions: During implementation, several participants underwent a vital change in terms of how they understood and enacted the duty of confidentiality. Before implementation, when lacking competence and experience in family involvement, maintaining patient autonomy and confidentiality was at the core of participants' professional practice, they experienced uncertainty in case of patient refusal and were faced by conflicting needs. During implementation, confidentiality issues was reframed, there was a changed weighting of principles and considerations, and core barriers dissolved.

(137) Title: No communication skills education, but clinical ethics education through applied drama.

Authors: Kenji Hattori, MD DMedSc MA. Gunma University School of Medicine.

Abstract:
In medical educational settings, while the amount of cutting-edge medical science knowledge to be taught is increasing, at the same time,

the level of practical competencies that learners should acquire is also getting higher. Medical school faculty are nowadays eager to teach communication skills. This is because, in addition to the tendency that medical students' interpersonal competency is poor in general, medical interviewing skills are evaluated by the standardized Objective Structured Clinical Examination before the clinical clerkship begins. Thus, education to develop standard interviewing techniques and communication skills become prevalent. Simply patterned protocols are commonly used there. This is problematic. Such protocols lead students to think in patterns and behave based on manuals. Recall how the four-principle doctrine affected medical professionals in the early days of bioethics, to which clinical ethics advocated a bottom-up approach. Instead of communication skill education, clinical ethics education through applied drama should be provided. However, clinical ethics here does not imply clinical ethics of discursive or deliberative type. Rather, it refers to micro-clinical ethics in vivo. However, this resides only in actual interactions among persons concerned in clinical settings. Micro-clinical ethics in vivo exists in conversations, facial expressions, gestures, attitudes, and the like. This is why applied drama should be utilized for educating micro-clinical ethics. Utilizing applied drama in medical school is not yet popular but promising. In this paper, the two types of educational program are to be introduced and demonstrated in video clips: clinical theater and clinical etude. Clinical theater was developed inspired by Augusto Boal's Forum Theater. Clinical etude is its modified form suitable for small group learning.

(138) Title: Analogical reasoning, morisprudence and moral distress during moral case deliberation on adult and pediatric intensive care units: preliminary results of an ethnographic study

Authors: Niek Kok MSc, Astrid Hoedemaekers PhD MD, Hans van der Hoeven PhD MD, Malaika Fuchs MD, Marieke Zegers PhD, Jelle van Gurp PhD, Radboud University Medical Center and Canisius Wilhelmina Hospital, Nijmegen, The Netherlands

Abstract:
Objectives: Through careful cross-case analogical reasoning, intensive care unit (ICU) professionals become more sensitive to ethical considerations in morally distressing cases. Analogical reasoning may result in morisprudence, an evolving collection of moral considerations across ethical cases historically encountered within an organization. Morisprudence helps professionals to learn live with moral distress and moral uncertainty as inherent to working on the ICU.
Design: This ongoing prospective ethnographic study is a sub study of a project on moral case deliberation, learning and moral distress. Presently, over fifty moral case deliberations have been recorded and transcribed.
Participants: 18 prospective moral case deliberations were selected for in-depth analysis, around which we interviewed 30 ICU professionals. Transcripts are coded using atlas.ti.
Setting: Five adult ICUs and one pediatric ICU in two hospitals in Nijmegen, the Netherlands.
Results: Professionals use analogies during moral case deliberation in several ways. First, patients are reasoned about in terms of past patients from professionals' practice. For example, prolonging treatment for a young patient with frontal lobe syndrome was deemed acceptable in light of a previous comparable patient, who is still recovering but has shown great gratitude. Past patient cases not only yield information about the appropriateness of earlier decisions, but also help unwind moral distress, by illustrating that cases can have good endings despite present difficulties.
Second, patients were reasoned about in terms of classes of encountered patients. For instance, a locked-in patient's prospective quality of life was reasoned about in terms of spinal cord injury patients, who gradually adjust their quality of life perception to their new, worsened somatic situation. Such analogies address moral uncertainty experienced during care in present patient cases.
Third, carefully comparing a patient to relevant research populations leads to differentiating the specific patient from the 'average patient'. This helps addressing moral intuitions that are based on false assumptions, leading to more moral certainty.

(139) Title: Awareness of diagnosis and prognosis in palliative care.

Authors: Federico Nicoli1,2, Claudia Bolpagni2, Patrizia Borghetti2, Michele Fortis2 1Center for Clinical Ethics, Insubria University, Varese, Italy; Clinical Ethics Service, Domus Salutis Clinic, Teresa Camplani Foundation, Brescia, Italy. 2 Hospice and Palliative Care Department, Domus Salutis Clinic, Teresa Camplani Foundation, Brescia, Italy.

Abstract:
The awareness of diagnosis and prognosis promotes therapeutic alliance and physician-patient-caregiver communication. In Palliative Care, awareness increases the quality of care at the end of life and supports a truthful relationship between physician, patient, and caregiver (therapeutic alliance): awareness of diagnosis and prognosis is a "necessary" pre requisite both for effective sharing of clinical and therapeutic decisions and for making more informed choices about end-of-life care, anyway the patient is not always aware of it.
The degree of awareness, as part of a dynamic process, can be influenced not only by the quality and quantity of information received, but also by psycho-social factors related to the personal history of the patient and family members. The literature presents a variety of ways in which prognosis awareness is investigated. The need to define a prognostic awareness during the course of care of the patient with advanced disease emerges from all studies, despite the multifaceted definitions of prognosis awareness and the limitations of the various methods to communicate with patient and family and caregiver.
This work aims to highlight the clinical and ethical matters about the awareness of diagnosis and prognosis, also considering the needs and the requests of the patient, which may vary in relation to the progression of the disease.

Parallel Sessions 4
Room: 5MTG
Chair: Silvia Ceruti

(140) Title: A feminist approach to autonomy in clinical practice

Authors: Dani O'Connor, PhD student, Cardiff and Bristol Universities

Abstract:
This paper seeks to address the impact of gender on a person's ability to exercise their autonomy within clinical practice, by drawing on feminist approaches to bioethics and theories concerning gender equity and social constructionism. This abstract will set the background for the paper, which will argue that owing to economic, social and cultural factors, women face greater difficulties when attempting to exercise their autonomy in clinical practice. In terms of healthcare, equity is a central issue which represents connections between poverty, disadvantage, oppression and poor health. The female gender represents a risk

factor for increased inequity; the implications of gender discrimination and poverty directly impact the ill health of women. These correlations occur throughout a woman's life cycle from; female infanticide, inadequate food and medical care, physical abuse, genital mutilation, forced sex and early childbirth. Further still, limits exist which make it harder to conquer and eradicate the problems caused by gender inequity. Work is often split into two categories, domestic labour and manual labour. Manual labour relates to work that is performed outside of the home which generates an income. Domestic labour is work which is done within the household, such as childcare, food preparation and cleaning. Generally, men are much more likely to participate in manual labour than women are and productive work usually brings greater autonomy and decision-making power. This discussion has begun to illustrate how societal, cultural and financial factors can greatly impede upon a woman's ability to act autonomously. The paper will build upon this narrative to explicitly show such factors are particularly relevant in terms of health care and medical decisions. For example, how financial restraints can physically impede upon a woman's ability to ask for help in relation to medical treatment; how gender stereotypes can impact upon a woman once she has sought medical advice and how the treatment then offered does not necessarily align with the wishes of the female patient. The conclusion of this paper will argue that gender presents a barrier to the dialogue of autonomy in clinical practice.

(141) Title: Towards a defensive bioethics? Issues from the Italian context

Authors: Leopoldo Sandonà, Facoltà Teologica del Triveneto (Vicenza-Padova) - Fondazione Lanza (Padova)

Abstract:
In recent legislative developments, even in Italian context, the role of clinical practice, especially the role Clinical Ethical Committees, risks to be subjected to a dangerous drift of "defensive bioethics".
Although in the formulation of end-life law (Ddl n. 2553) was chosen the cautious formula of "clinical evaluation committees" [Comitati di valutazione etica] to indicate the Committees to evaluate the criteria for access to medical assisted death/suicidio [morte/suicidio medicalmente assistita/o], according to the indications of the Italian Supreme Court in judgment 242/2019, however, the danger that Clinical Ethics Committees, and in their absence the Research Ethics Committees, are called to evaluate ethical-clinical cases-histories, not so much in the conduct and follow-up, but "ex post", ratifying a path already taken in other institutions, becoming only the "endorsement" for the clinical decision or even for the intervention of the deputy judge. Therefore, we can find a confusion between "Clinical evaluation Committees" and Clinical Ethical Committees, as in the a.7 c. 2 of the new law the Clinical evaluation Committees are described as multidisciplinary Committees.
This trend also leads to a subjective attitude of the Committees themselves of a defensive nature, with a proliferation of arguments which are not strictly ethical, but above all legal, and pointing to the primary objective of avoiding legal cases. In addition, the other functions of the Committees, particularly those of clinical practice, are in danger of being undermined, since the training of health professionals and information to public opinion, which is the first element in establishing a bioethical awareness and the recognition of ethical and clinical histories, becoming an ancillary element in a context that brings to the attention of Committees media cases of public impact, as shown by recent cases in Italian context. Another defensive element is the organisational one, appointing Committees predominantly composed not with experts in bioethics, but with legal-defensive attitude. In this context, there is also the different role of the two involved Committees, deliberative for Research Ethics Committees, advisory for Clinical Ethics Committees.

(142) Title: Creating an ethical community in a large academic hospital

Authors: R.L. van Bruchem-Visser, MD, PhD, Department of Internal Medicine, Erasmus Medical Center Rotterdam, the Netherlands; S. van de Vathorst, PhD, Department of Medical Ethics, Philosophy and History of Medicine, Erasmus Medical Center Rotterdam, the Netherlands

Abstract:
In the Erasmus Medical Center Rotterdam, a large academic hospital, complex medical decisions are made every day. This calls on the moral reflectivity of healthcare professionals. Ethical dilemmas play an important role with every ethical dilemma being unique, as is every patient. At the moment, there is no formal structure in the Erasmus Medical Center to address these medical ethical dilemmas.
A group of ethicists and physician-ethicists have proposed a clinical ethical service consisting of an expert team (Erasmus MC Expert team of Ethics) and an ethical community of ambassadors throughout the hospital of (among others) physicians, nurses and policymakers. The ambassadors of (medical) ethics will be trained twice a year and will function as antennae for (medical) ethical dilemmas. Members of the expert team will be available to assist in moral deliberation sessions. Research will be conducted on the reported (medical) ethical ethics, thus providing insight in existing ethical dilemmas in the hospital.

(143) Title: Nonhuman health – a proposal to conciliate anthropocentric and non-anthropocentric conceptions of One Health

Authors: Felicitas Selter, PhD & Prof. Dr. med. Dr. phil. Sabine Salloch (both: Institute for Ethics, History and Philosophy of Medicine, Hannover Medical School, Germany)

Abstract:
The COVID-19 pandemic has reinforced the need to take a global perspective in bioethics, especially when it comes to zoonotic diseases. Early on, the importance of the One Health approach was pointed out in this context. One Health (OH) emphasizes the interconnectedness between the health of humans, animals and the environment. Here, the focus will be on animal health and its relation to human and, above all, public health. OH conceptions have been roughly categorized into two groups: some remain anthropocentric at their core in (explicitly or implicitly) saying that the need for drawing attention to non-human health has an instrumental value in promoting public - i.e. human - health. Non-anthropocentric approaches, in contrast, attribute an intrinsic value to non-human health or wellbeing as well.
We will argue that this distinction is too crude. OH can plausibly attribute an intrinsic value to non-human health and be anthropocentric in the last consequence. This need not be ethically inconsistent if it is accepted that animal health in the OH approach can be understood both as an end in itself and as a means to an end. Animal health, according to this proposal, has an intrinsic value that is independent of whether or not it is beneficial to human health. There are cases where animal health should be promoted, even if humans would not directly benefit or even be negatively affected. However, certain exceptional circumstances may arise in which animal health is first and foremost – though not exclusively - viewed as a means to an end (in terms of its impact on public health), e.g. in a highly lethal zoonotic disease spreading from wild-living animals onto humans. Such an understanding of OH would continue to be ultimately

anthropocentric, but without biting the bullet that animal health has no intrinsic value at all. This, in turn, could initiate an honest debate on how far we are prepared to go in respecting this value. Possible scenarios will be introduced and critically discussed with concern to their practical consequences for human patients and public health.

(144) Title: Cultures and Cures: Neurodiversity and Brain Organoids

Authors: Andrew J. Barnhart, Kris Dierickx, Centre for Biomedical Ethics and Law, KU Leuven, Belgium

Abstract:
Background: Research with cerebral organoids is beginning to make significant progress in understanding the etiology of autism spectrum disorder (ASD). Brain organoid models can be grown from the cells of donors with ASD. Researchers can explore the genetic, developmental, and other factors that may give rise to the varieties of autism. Researchers could study all of these factors together with brain organoids grown from cells originating from ASD individuals. This makes brain organoids unique from other forms of ASD research. They are like a multi-tool, one with significant versatility for the scope of ASD research and clinical applications. There is hope that brain organoids could one day be used for precision medicine, like developing tailored ASD drug treatments.
Main body: Brain organoid researchers often incorporate the medical model of disability when researching the origins of ASD, especially when the research has the specific aim of potentially finding tailored clinical treatments for ASD individuals. The neurodiversity movement—a developmental disability movement and paradigm that understands autism as a form of natural human diversity—will potentially disagree with approaches or aims of cerebral organoid research on ASD. Neurodiversity advocates incorporate a social model of disability into their movement, which focuses more on the social, attitudinal, and environmental barriers rather than biophysical or psychological deficits. Therefore, a potential conflict may arise between these perspectives on how to proceed with cerebral orga- noid research regarding neurodevelopmental conditions, especially ASD.
Conclusions: Here, we present these perspectives and give at least three initial recommendations to achieve a more holistic and inclusive approach to cerebral organoid research on ASD. These three initial starting points can build bridges between researchers and the neurodiversity movement. First, neurodiverse individuals should be included as co-creators in both the scientific process and research communication. Second, clinicians and neurodiverse commu- nities should have open and respectful communication. Finally, we suggest a continual reconceptualization of illness, impairment, disability, behavior, and person.

Parallel Sessions 4
Room: 6MTG
Chair: Silvia Siano

(145) Title: Assisted suicide: Italy and Spain confronted between legal battles and legal provisions

Authors: Dei Medici S. MD, Casella C. PhD, Policino F., MD, PhD, Marisei M., MD, Auriemma G., MD , Di Lorenzo P., MD, PhD, Capasso E., MD, PhD, Niola M., MD- Full Professor- Dep. of Advanced Biomedical Science- Legal Medicine- University Federico II- Naples

Abstract:
By "assisted suicide" we mean the practice of consciously putting an end to one's existence by self-administering lethal doses of drugs by a person who is "assisted" by a doctor.
In Italy, the sentence 242/2019 of the Constitutional Court has identified four requisites that can justify an aid to suicide: the presence of an irreversible pathology; severe physical and mental suffering; the full ability to make free and informed decisions; dependence on life-sustaining treatments.
On March 26, 2021, the first case of a request by a 43-year-old quadriplegic patient who had requested access to assisted suicide occurred in Italy.
The tortuous process is the result of the decision of the Court of Ancona after a complaint for failure to activate the procedures indicated by the ruling of the Constitutional Court.
Only in November 2021 Mario obtained the favorable opinion of the Ethics Committee and in February 2022 the choice of the drug and the methods of administration arrived.
The situation is different in neighboring Spain, where on March 18, 2021 the Spanish Parliament definitively approved the law that legalizes euthanasia and assisted suicide.
The salient features that characterize the main differences between Italy and Spain will be fully illustrated.

(146) Title: Emerging Technologies and Vulnerabilities in Aged Care: a Systematic Review of Qualitative Evidence

Authors: Virginia Sanchini (first/corresponding author), PhD, RTD A, Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy; Annachiara Fasoli, Research Fellow, Department of Oncology and Hemato-Oncology, University of Milan, Milan, Italy; Chris Gastmans, Full Professor, Centre for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven, Leuven, Belgium.

Abstract:
In recent years, a great emphasis has been placed by policymakers, innovators, health and care systems administrators on Emerging Technologies (ET) designed for the elderly. An ensuing, vast amount of both theoretical and empirical literature has appeared exploring the ethical implications of ET in the context of daily management and care of (frail) older adults. However, to the best of our knowledge, no comprehensive research has been carried out, as of yet, over the impact of ET on older adults' vulnerability, in particular exploring the viewpoints of older adults themselves. To fill this gap, we set out to conduct an in-depth examination of the empirical literature reporting older adults' perspectives about the (positive as well as negative) impact of ET on their vulnerabilities.
Method. Using PRISMA procedure, we conducted a systematic review of empirical (namely, qualitative) publications in five major databases (Pubmed, Embase, Web of Science, CINAHL and Philosopher's Index) of biomedical, philosophical, bioethical, and anthropological literature, that focused on older adults' vulnerabilities exacerbated and/or tamed by ET. 11.631 results were obtained. Results were screened and duplicates were eliminated. We are now in the process of abstract screening. All included articles will be then critically analysed; data extraction and synthesis will be performed according to the five preparatory steps of the QUAGOL methodology. The results of this analysis process as well as a critical reflection on the results will be presented at the EACME 2022 conference.

(147) Title: Extended patient journey in patients over 70 years of age referred to the Emergency Department

Authors: R.N.E. Strijker, Bsc of Medicine, Erasmus MC, Rotterdam, Netherlands. R.L. van Bruchem-Visser, Phd MD, Department of Internal Medicine and Geriatrics, Erasmus MC, Rotterdam, Netherlands

Abstract:
Introduction: The number of patients visiting the Emergency Department older than 65 years old is currently 33%, and expected to rise even further. By exploring patient journeys quality of care can be improved, and understanding can be learned. In this study we aim to examine the experience patients of the care process around their illness.
Methods: Patients over 70 years old will be interviewed on arrival at the Emergency Department of Erasmus Medical Centre, Rotterdam, and asked about the experience of care leading up to the visit to the Emergency Department. One week later another interview will take place. Three patients will be followed: one admitted, one discharged and one transferred to a nursing home. Interviews are transcribed verbatim and analyzed by using QRS NVivo 12 software. Ethical approval was obtained.
Results: Study is currently ongoing, results will be presented at the conference.

(148) Title: The role of physicians during torture. An ethical question

Authors: Giovanni Rasori student (o PhD candidate), Department of Biotechnology and Science of Life, Center for Clinical Ethics, Insubria University (o University of Insubria) Mario Picozzi Director of the Center for Clinical Ethics, Biotechnology and Life Sciences Department, University of Insubria (Varese, IT)

Abstract:
Military medical ethics have been challenged by the post-September 11, 2001 "War on Terror." Frequently asked questions are whether military doctors are officers first or doctors first and whether military doctors need a separate code of ethics . This work examines how the War on Terror has influenced the way we have dealt with these questions since 2001. Two examples frame this discussion: the use of military doctors to force-feed hunger strikers detained in the prison camps. and the use of non-vital treatment of prisoners as a bargain for their information. The concept of double loyalty that doctors can have both towards a patient and a third party is important in clarifying the obligations of doctors. The extent to which loyalty can be diverted from a patient to a third party (such as a prison commander) is greatly underestimated. The concept of double loyalty was examined in civilian and military contexts and the principles of public health ethics were used to build a framework for determining the legitimacy of doctors' obligations. What weight does medical ethics have in relation to the morality of society regarding torture? In the complex military context, should independent ethical courts be created to judge conflicts of loyalty? This essay wants to analyze these issues.

Parallel Sessions 4
Room: 8MTG
Chair: Elena Ferioli

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(149) Title: The value-free ideal of science: a useful fiction? A review of non-epistemic reasons for the research integrity community

Authors: Jacopo Ambrosj, PhD student at Center for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven
Co-authors: prof. Kris Dierickx, Center for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven •prof. Hugh Desmond, Institute for the History and Philosophy of Science and Technologny, CNRS/Paris I-Sorbonne, and Department of Philosophy, University of Antwerp

Abstract:
In order to effectively inform public health policies, biomedical sciences need to enjoy the trust and meet the expectations of the general public. But what are these expectations? Generally speaking, the public expects researchers not to be guided by non-scientific interests. As emerged during the COVID-19 pandemic, the slightest suspicion (whether warranted or not) that this is not the case can breach the trust of the public (or at least of a portion thereof). Can researchers meet these expectations? Nowadays, philosophers of science reject the view, traditionally represented by the so-called value-free ideal (VFI), according to which proper science is never influenced by non-epistemic values. Nevertheless, were this ideal to be unattainable, striving for it could still be close enough to the expectations of the public, and possibly lead to other benefits. In other words, one could ask: can the VFI be considered a useful fiction? Answering this question can contribute to our understanding of ethics and research on a multidisciplinary level. In fact, to address this question one must address issues such as the guiding values of researchers, and their relation with the public, that are crucial for scholars and institutions involved in different fields, including research integrity.
In this review, we identify the main non-epistemic (moral, cultural, political…) reasons for or against the VFI discussed by scholars. These reasons are concerned with the impact that the VFI would have on society, policy-making, or the scientific community itself, with some authors appealing to the same principles to argue for opposite positions. For instance, it has been argued both that maintaining the VFI improves public trust in science, and, conversely, that being transparent about the role that different values play within science is the only way to be trustworthy. Though most of the reviewed articles do not endorse the VFI, they seem to agree that some constraint has to be put on the role played by economic interests and political ideologies. Other than this, it is not possible to determine whether or not the VFI would benefit- among other things- public trust and research integrity in every situation.

(150) Title: Composition and capacity of Institutional Review Boards, and challenges experienced by members in ethics review processes in Addis Ababa, Ethiopia: An exploratory qualitative study

Authors: Yemisrach Zewdie

Abstract:
Few studies in sub-Saharan Africa evaluate Institutional Review Boards (IRBs) capacity. The study aims to explore the composition of IRBs, training, and challenges experienced in the ethics review processes by members of research institutions and universities in Addis Ababa, Ethiopia. Our findings indicate that most IRBs members were trained on research ethics and good clinical practice. However, majority perceived the trainings as basic. IRB members faced several challenges including: investigators wanting rapid review; time pressure; investigators not following checklists; limited expertise in reviewing clinical trials, studies on genetics, and traditional medicine; lack of IRB offices for administrative work; competing tasks; limited staffing and the lack of a standardized review system. There is need for advanced training on research ethics to meet the evolving research needs. In addition, investments in IRBs are needed in terms of funding, and physical and human resources in Addis Ababa and Ethiopia in general.

Keywords: Institutional Review Boards, sub-Saharan Africa, capacity, resources, challenges

(151) Title: Development of a MOOC on Research Ethics

Authors: Patricia Cervera de la Cruz, Alice Cavolo, Dorothea Chatzikonstantinou, Chris Gastmans, Kris Dierickx, Pascal Borry, Centre for Biomedical Ethics and Law, Department of Public Health and Primary Care, KU Leuven

Abstract:
The COVID-19 pandemic led many of us to explore the world of online education. Enrolments for Massive Open Online Courses (MOOCs) on platforms like edX, Coursera or Udemy, surged (Shah, 2020). Now, more than ever, the educational potential of these digital platforms is palpable. With 24 published MOOCs and more in development, KU Leuven is part of the innovating institutions promoting this new type of learning.
In the context of MOOCs, bioethics is an underrepresented field. At this moment, we are in the process of developing a MOOC on the topic of *Research Ethics*. The course fits within our Master of Bioethics. The course will be part of the first MOOCs for credits that KU Leuven will launch, making it one of its kind. This type of MOOC will give the opportunity to earn a KU Leuven study credit after you successfully complete the MOOC with the learning activities and evaluation.
The goal of this presentation is to explain the characteristics of the MOOC, the target audience and the process of designing the course, from initial planning phases to more concrete considerations of content creation. In this framework, we will explain the ABC learning design method, and the hands-on-course development strategy.
Following this, we will discuss the content production and the formats used, such as interviews, knowledge clips and more. In particular, we will focus on the collaborative opportunity that MOOCs can offer within bioethics research teams. Finally, we will discuss the evaluation strategy in our course. Throughout the presentation, we will show how MOOCs can enhance students' understanding of bioethics topics, such as *Research Ethics*.

(152) Title: The Balancing Act: weighing rights of patients and at-risk relatives in policy approaches to nondisclosure of genetic risk

Authors: Amicia Phillips (PhD student, KU Leuven), Danya Vears (Post-doc researcher, University of Melbourne, KU Leuven), Ine Van Hoyweghen (Professor, KU Leuven), Pascal Borry (Professor, KU Leuven)

Abstract:
Genome sequencing can uncover genetic risk information with important implications not just for patients, but also their relatives. Such information may indicate that a relative is at risk of developing the condition or passing the condition on to their children, and thus informing relatives may play a key role in initiating diagnosis, treatment, or access to reproductive screening technologies. Patients' decisions to (not) disclose genetic risk information to their relatives pose ethical challenges and can lead to conflicting interests and rights between both parties. Several countries have guidelines or legislation attempting to address the issue of disclosure/nondisclosure, which can be categorized into three main approaches: 1) disclosure is the patient's obligation; 2) disclosure is the clinician's obligation; 3) disclosure is within the clinician's purview to decide whether to inform relatives, in cases where the patient has not consented to disclosure. In many countries, there is no specific guideline or law, meaning it is unclear what rights and duties patients and clinicians have towards relatives. Using Belgium as an exemplary case, we analyzed existing national legislation and compared it with international precedent. We then explored ethical arguments for and against various policy approaches. This ethical analysis is supported by data from our empirical research in which Belgian clinicians were asked their opinions regarding potential national policies. Based on our findings, we recommend the development of clearer policy to help clinicians and patients understand how to fulfill their rights and duties to at-risk relatives.

Parallel Sessions 4
Room: 9MTG
Chair: Denier Yvonne

(153) Title: Clinical trials in fetal medicine: between safety and psychosocial benefits.

Authors: Daniel Pizzolato, PhD candidate, KU Leuven/ Dr. Neeltje Crombag, KU Leuven/ Prof. Dr. Jan Deprest, University Hospitals Leuven/ Prof. Dr. Kris Dierickx, KU Leuven

Abstract:
Some similarities can be seen between fetuses affected by a severe congenital diaphragmatic hernia or other life-threatening pathologies and severely ill newborns. However, in fetuses, the context is complicated by its ethical status, its viability and its inter-dependency to its mother. Since well-tested post-natal treatments do not always provide a working option for the well-being of the newborn, in some cases, offering investigational fetal-maternal therapies can be seen as providing fetuses with the only valuable chance of survival. Some prospective parents perceive this as their last hope while accepting the uncertainties and the potential harm. This may contradict the ethical principles on which research and clinical care are based.
From a clinical research perspective, to provide the highest level of evidence and to guarantee the safety of new fetal-maternal treatments for both the fetus and the mother, is essential. However, from a clinical practice perspective, this may cause ethical dilemmas. For clinicians, prohibiting an investigational intervention with a (perceived) potential for survival of the fetus can be seen as prohibiting the attempt to take advantage of all benefits that the new potential therapy might have. Moreover, prospective parents may demand clinicians for treatment to fulfill their need to have done everything possible for their future child.
In considering the two opposite points of view about the possibility to offer the investigational intervention off-trial, we will present arguments in favor of and against it. On the one hand, arguments based on safety, the principle of non-maleficence, the responsibility of providing the highest level of evidence and public interest emphasize the need to restrict the use of the new intervention only within the trial process. On the other hand, arguments based on psycho-social benefits for the mother, the principle of beneficence, the concept of the 'right to try' and individual interest highlight the need to expand the use of the treatment outside the trial procedure. Besides being valuable in this specific maternal-fetal trial, this reflection about the expanded access to interventional treatments is relevant for any clinical trial in fetal medicine.

(154) Title: Review of normative documents on preimplantation genetic testing: recommendations for future guidance of polygenic embryo testing

Authors: Maria Siermann (main presenter, PhD student, KU Leuven/ University of Helsinki), Olga Tsuiko (post-doc, KU Leuven), Joris Robert Vermeesch (professor, KU Leuven), Taneli Raivio (professor, University of Helsinki), Pascal Borry (professor, KU Leuven)

Abstract:
Recently, preimplantation genetic testing for polygenic conditions has been developed and introduced commercially. This technology aims to screen embryos for the risk of developing certain polygenic disorders, e.g. diabetes, cancer or schizophrenia. Polygenic embryo screening is ethically contentious, and questions are raised around its clinical utility, the difficulties of accurately informing prospective patients, the complexities of navigating risk scores for multiple conditions with varying presentations, the possibility of screening for non-health related traits such as height and intelligence and the technology's lack of inclusivity for people of non-European ancestry.
Guidelines for the emerging technology of polygenic embryo screening are currently lacking but are crucial to consider before further availability. We therefore performed a systematic review of normative documents on the already established preimplantation genetic testing for monogenic conditions. The aim of analysing normative guidelines and recommendations was to understand what the current consensus is on ethical acceptability of preimplantation genetic testing for monogenic conditions and to what extent this can be applied to preimplantation genetic testing for polygenic conditions.
38 normative documents at the national, European and global level were included in the analysis. We identified two themes: 1) what preimplantation genetic testing is seen as appropriate for; and 2) who can make decisions regarding the use of preimplantation genetic testing. Many aspects of documents on preimplantation genetic testing for monogenic conditions apply to polygenic embryo screening as well. However, the fact that the latter can screen for the risk of developing multiple polygenic conditions increases ethical difficulties regarding severity, risk, autonomy and informed decision-making and complicates the ethical navigation of preimplantation genetic testing for polygenic conditions.
Based on our analysis of existing normative documents, we conclude that ethical acceptability for preimplantation genetic testing of polygenic conditions is limited. Our findings present various factors that have to be considered for the development of guidelines and the appropriateness of polygenic embryo screening.

(155) Title: Feasibility of measuring informed choice with regard to reproductive genetic carrier screening for autosomal and X-linked recessive monogenic condition

Authors: Eva Van Steijvoort (PhD Candidate, KU Leuven), Prof. Pascal Borry (KU Leuven)

Abstract:
Through reproductive genetic carrier screening couples at-risk of conceiving a child with an autosomal recessive or X-linked condition can be identified prior to conception, allowing prospective parents to make reproductive decisions when planning for a family. While new genomic technologies allow to screen for an ever-increasing number of disease-causing variants many ethical, legal and social questions still remain unanswered. Should reproductive genetic carrier screening be available during pregnancy or only before conception – and which reproductive options should be available for which conditions screened for? Which conditions should be included in carrier screening test panels? Is it sufficient to provide couple-based results or is it necessary to report all individual test-results? Some have questioned whether people will be able to make an informed choice with regard to larger test panels including multiple genes associated with autosomal recessive and X-linked conditions. Moreover, concerns have been raised that routinely offering reproductive genetic carrier screening could lead to less critical reflection on whether reproductive genetic carrier screening is appropriate to consider, and which results would be relevant to have for further reproductive decision-making. Professional organizations have emphasized that the success of reproductive genetic carrier screening should not solely be measured by the uptake of screening. An assessment of whether or not individuals are making informed choices with regard to reproductive genetic carrier screening free from coercion from others is considered to be at least as important. To gain more insights into the complexity of the decision-making process of reproductive-aged couples regarding preconception reproductive genetic carrier screening we performed a prospective study where this was offered free of charge. A modified Multidimensional Measure of Informed Choice was used to determine whether couples who opted for reproductive genetic carrier screening made an informed choice. According to our modified version, 82% of our study participants made an informed choice. Uninformed choice among study participants occurred mostly due to insufficient knowledge (18.2%). Future research should try to assess if high levels of informed choice can also be achieved outside a controlled research context with more limited resources.

(156) Title: What makes a next-generation sequencing result a diagnosis? A multi-site case study

Authors: Janneke M.L. Kuiper (PhD fellow, Life Sciences and Society Lab, Centre for Sociological Research, KU Leuven) & prof. dr. Ine Van Hoyweghen (Life Sciences and Society Lab, Centre for Sociological Research, KU Leuven)

Abstract:
The latest DNA testing technologies, next-generation sequencing (NGS), allow to sequence the whole exome or even whole genome at once. Allowing for significantly more diagnoses to be made, but also heightening the chances of having to deal with more complex and uncertain results. Where a diagnosis is often expected to bring about information on causality, treatment and prognosis, this is often not the case for even the more certainly pathogenic NGS results. Drawing on extensive fieldwork in two European human genetics centers, this paper explores the boundaries between 'a result' and 'a diagnosis' for variants that are deemed (partially) causative of a patient's symptoms. Through a qualitative analysis of observations in clinical consultations and multidisciplinary team meetings and semi-structured interviews with healthcare professionals (HCPs) and patients, we examine when a causative genetic variation is presented and perceived as 'a result' and/ or as 'a diagnosis'. We explore which factors play a role in making this distinction in clinical practice and how it is subsequently taken up by patients and discuss the clinical and social power of either a result or a diagnosis. We assess why knowing the illness's origin is a prominent concern for many patients and argue how this might be related to the successful positioning of genetics as the 'privileged site of understanding the origins of abnormality' (Navon 2019: 292). We show how this hegemony is reinforced through the language used around genetic variation and the enactment in the practices of care, where HCPs and patients are entangled in keeping the search for genetic difference highly

relevant. In doing so, we further the understanding of what is at the core of a (genetic) diagnosis. Furthermore, we stress the wider politics of care involved in making the often poorly understood genetic variations relevant and question who ultimately benefits from this.

(157) Title: What should be included in consent for an innovative surgical procedure? Lessons learnt through innovation in gynaecological surgery.

Authors: Dr Naomi Holbeach MRMed, MBBS (Hons), LLB (Hons), BSc. Lecturer (Level B), Department of Obstetrics and Gynaecology, University of Melbourne, Melbourne, Australia

Abstract:
Consent for innovative surgical procedures presents a significant ethical and legal challenge to surgeons and patients. The case of Mills v Oxford University Hospitals NHS Trust [2019] EWHC 936 demonstrates the importance of consent to innovative surgical procedures. Unlike in the case of established surgical procedures, innovative procedures carry the added complexity of potentially less safety and efficacy data, the risk of unknown outcomes, and variable surgeon and theatre team experience. In Mills the importance of preoperative counselling in the setting of surgical innovation was made clear and these lessons can be applied to numerous other settings where innovation is introduced in health care. Recent experiences in gynaecology, for example the introduction of vaginal mesh and its disastrous consequences for many women, offer opportunities to learn from past mistakes and acknowledge the importance of preoperative counselling and consent in the setting of surgical innovation.
Despite the long history of innovation in surgery, surgical innovation presents a challenge for the consent process especially where it is being performed outside of a clinical trial. Recent legal action and patient complaints can offer insight into the evolving expectations by courts, professional bodies, and patients with respect to pre-operative discussions regarding novel procedures. By analysing case law and disciplinary proceedings alongside the medical literature, it can be concluded that whilst the legal and ethical obligations are likely the same for innovative procedures as for established procedures, we must acknowledge that something more than usual pre-operative discussion and advice is required to satisfy those obligations in the case of innovation. Greater guidance is therefore needed for surgeons to engage in the consent process and provide patients with enough information to make an informed choice whether to bear the risk of the less tested procedure. This presentation will offer suggestions on the content and form that preoperative counselling and consent to innovative surgery should involve.

Parallel Sessions 4
Room: 10MTG
Chair: Davide Battisti

(158) Title: Fostering moral resilience and moral competences using CURA, a clinical ethics intervention. An empirical mixed methods study.

Authors: Malene van Schaik Ma Msc, Dr. H.Roeline Pasman, Prof. dr. Guy Widdershoven, Dr. Suzanne Metselaar. Amsterdam UMC

Abstract:
Introduction: CURA is a clinical ethics support instrument that aims to foster palliative care professionals' moral resilience and to improve quality of palliative care. 'CURA' is an acronym and prescribes four steps for ethical reflection: Concentrate, Unrush, Reflect and Act. We trained healthcare professionals as 'CURA ambassadors' to facilitate ethical reflection using CURA in small group settings in clinical practice. The aim of this study is to examine the impact of CURA on the moral competences, moral team work and moral action, as well as on moral resilience of palliative care professionals.
Method: Mixed method study using a questionnaire and interviews. A pre–post study was conducted using the EURO-MCD scale and the Rushton Moral Resilience Scale (RMRS-NL). Pre-study was completed by 71 CURA ambassadors. Post-study results are expected in August 2022. 12 semi-structured interviews with 'CURA ambassadors' (n=6) and their colleagues (n=6) will be conducted to interpret the results of the quantitative measurements and make recommendations.
Results: The 'CURA-ambassadors' worked in various settings of palliative care: such as home care (12/17%), nursing homes (27/38%), hospice care (7/10%) and hospital setting (23/32%). Participants worked as licensed practical nurse/healthcare assistant (20/28%), registered nurse (19/27%), specialized palliative care nurse (10/14%), and spiritual counselor (8/11%). Overall means of moral resilience was 2.89 on a 4-point scale. Results of the post study and interviews are expected in August 2022.
Discussion: The means score of Moral Resilience in our study was reasonably high. Our mixed methods post study will deliver more insight in how to strengthen and retain moral resilience and moral competences.
Ample research has focused on the causes of moral distress and its detrimental effects on quality of care and professionals' wellbeing. However, it is unlikely that moral distress can be fully eradicated from clinical practice. A shift towards fostering moral resilience and moral competences has been proposed as the way forward to limit the effects of moral distress. However, more research is needed to assess successful strategies to increase moral competences and moral resilience among nurses.

(159) Title: Social exclusion of people who abstain obligatory COVID 19 vaccination for medical reasons: A contemporary ethical dilemma.

Authors: Dr Tsagdi, Dr Alifieri, Prof. Theologou Kostas, Dr Grigoriadou,Dr Balatsou, , National Technical University of Athens.

Abstract:
The measures of obligatory vaccination against COVID19 disease in Greece, have failed to cater for people, who for serious medical reasons, were prohibited by their private doctors to be vaccinated. This fact, however, leads to their unwilling social seclusion, since they cannot obtain the vaccination certificate that ensures access to all social activities. They are, therefore, faced with the dilemma of consenting to vaccination, disregarding possible health even fatal consequences, or social exclusion and isolation. The aim of this research study is to discuss this ethical conflict, between what is considerate ethical for the society in contrast to restriction of personal will and health. It wishes to rediscover the very essence of commitment to protecting human rights-health and social well- being. This dilemma will be viewed and examined under the scope of core ethical values and principals met in Hippocrates oath and the fundamental ethical theory of Utilitarianism. The study will try, drawing from these ethical theories and definitions, to test these questions and conclude on what is the indicative ethical choice. The study wishes to purpose suggestions of measures that can be taken, in order to ensure equal operations for all citizens,

based on medical ethics and self -disposition principles. It will also propose actions that should put in the equation sensitive groups. We feel that a balanced ethical approach that does not accentuate disparities within and among different groups, could ensure health equality, better social resilience and commitment to effective prospective preparedness.

(160) Title: Value choices in European COVID-19 vaccination schedules: how vaccination prioritization differs from other forms of priority-setting

Authors: Karolina Wiśniowska, PhD student, Jagiellonian University; Tomasz Żuradzki, PhD, Jagiellonian University; Wojciech Ciszewski, PhD, Jagiellonian University

Abstract:
With the limited initial availability of COVID-19 vaccines in the first months of 2021, decision-makers had to determine the order in which different groups were prioritized. Our aim was to find out what normative approaches to the allocation of scarce preventive resources were embedded in the national COVID-19 vaccination schedules. We systematically reviewed and compared COVID-19 vaccination prioritization regulations in 29 countries: 27 European Union members, the United Kingdom, and Israel. We differentiated between two main types of priority categories: groups that have increased an infection fatality rate (IFR) compared to the average for the general population and groups chosen because their members experience increased risk of being infected (ROI). Our main findings show a clear trend: all researched settings prioritized criteria referring to individual IFR (in particular being over 65 years old and coexisting health conditions) over the ROI criteria (e.g. occupation and housing conditions). This is surprising since, in the context of treatment, it is rather common and justifiable to adopt very different allocation principles (e.g., introducing a saving more life-years approach or prioritizing younger patients). We discuss how utilitarian, prioritarian, and egalitarian principles may be applied to interpret these normative differences between the allocation of curative and preventive interventions.

(161) Title: Giving a voice to patients with a rare disease. Findings of an ongoing qualitative interview study.

Authors: Sebastian Wäscher, PhD, Institute of Biomedical Ethics and History of Medicine, University of Zurich

Abstract:
Background: Estimates assume that between 3.5% - 5.9% of the global population suffer from one of the over 7000 rare diseases. Although this equates to roughly 260-450 million affected people public and scientific attention for rare disease is still small. While rare disease programs have been established worldwide during the last decades research is still far from being saturated due to the broad variety and the small incidences per disease.
Aim: With our project we aim to deepen the understanding of the severe psychological, social, and physiological impact a rare disease can have on the affected individuals. Additionally, we give voice to these people by establishing a publicly available online-platform (dipex.ch) in which they share their personal experience in videoclips.
Method: We conduct semi-structured qualitative interviews and analyze them with a thematic analysis. Participants are selected based on a maximum variation sampling. We aim to reach a theoretical saturation within 40 interviews. The study is conducted in an iterative process that allows adjustments in course of the study.
Results: I will present the current status quo of the study by providing illustrative examples and giving insights into the ongoing interview process and analysis. The interviews already make evident that a specific fraction of rare disease patients share a phenomenon that can be described as diagnostic odyssey. As in Homer's odyssey patients describe their way to the diagnosis as a long, costly, and exhausting, however, also educational journey. During their journey patients typically see many different medical specialists who are rarely able to substantially help them. Patients feel that physicians are overwhelmed with the complexity and/or the peculiarity of their symptoms. As a result, the patients report that the physicians are only treating symptoms instead of searching for the underlaying reason of their malaise. Such experiences have severe impact on the persons lives in social, medical, and psychological dimensions.
Discussion: In a short discussion section, I will embed the empirical results into the bioethical debates on healthcare access, physician-patient relationship, and vulnerability. Based on the empirical and ethical analysis I will conclude with policy recommendations for the Swiss health care system.

(162) Title: Thinking in times of pandemic: the experience of mourning in nursing homes, between rupture and continuity

Authors: Le Berre Rozenn, PHD, Center of Medical Ethics, Lille Catholic University

Abstract:
Context and issues: Since the start of the pandemic, the situation of nursing homes has received particular attention, emphasizing the impact of health conditions on end-of-life support and bereavement. Many ethical questions arose there: how to comply with health standards while maintaining a human relationship and trust with people?
Method: The project, supported by La Fondation de France, aims to design training/support modules for nursing homes, from the perspective of a community of care, using the tools of research in human and social sciences. For this, we conducted an exploratory survey within three groups of nursing homes with various dimensions and characteristics. From March to July 2021, semi-structured interviews were carried out with residents and relatives who had gone through bereavement in the last 6 months. Focus groups were also carried out with support professionals.
Discussion and Perspectives: One of the major challenges of our work is to question the way in which the subject of mourning, in particular in the context of a pandemic, makes it possible to address issues relating to living together in the EHPAD. Issues related to mourning and loss question people's living and working conditions. Practices and discourses are also particularly questioned in their meaning and symbolism, in particular through the place and function of ritual practices.

Parallel Sessions 4
Room: 11MTG
Chair: Bert Molewijk, Margreet Stolper, Wieke Lichenberg

New directions for ethics support: an international panel session about developing and implementing Ethics Support Tools

Parallel Sessions 4
Room: 13MTG
Chair: Ruth Horn

(164) Title: Exploring Chinese bioethics through the Practice of Palliative Care – A Comparative study

Authors: Shengyu Zhao, PhD student, University of Bristol

Abstract:
The dualistic view of Western and Chinese cultures has been long-standing in the realm of social sciences. In this pair, Chinese culture, and Asian culture in broad, has often been alienated as 'the other' kind from mainstream Anglo-Saxon ethos. There is no exception in the field of bioethics. While thinking of the ethical challenges arising in palliative care, there are assumptions that the practice of Western (bio)ethical theories is unlikely to fit in the Chinese context. Instead, a distinct 'Chinese bioethics' is at work. Nevertheless, are the Chinese precepts and Western (bio)ethics fundamentally parallel with no overlaps? This project explores this question through a comparative analysis of Chinese and Western philosophy and palliative care practice. Taking the dominant Western ethical theories as reference, I argue that the two different cultures agree on most prima facie principles including beneficence, maleficence and justice. However, Chinese (bio)ethics is deeply indebted to Confucianism and familism, which displays a relational and collectivist outlook in nature. Ethical justifications in medicine often prioritise the family over individuals.
Despite of above statements, it is still too soon to conclude the relationship between Chinese and Western (bio)ethics. So far there has been modest horizontal research on these two different cultural backgrounds. The primary reasons, in addition to the language barriers and shorter history of palliative care development, include the lack of consideration to Chinese-specific customs, such as the death taboo and the family-centred care model. Palliative care delivery in China has largely mimicked the structure of the UK, therefore there are similar ethical challenges occurring and clinical responses undertaken. However, as an extension of familism, the concept of 'family autonomy' is imposed in Chinese medical decision-making which entitles the family to participate equally as the patient – or even dominate – the process. The family 'dictatorship' is criticised by mainly western bioethicists, yet without regard to the Confucian (bio)ethical values underpinning familialist practices. The debates can only be settled by empirically investigating the perspectives of those involved in the delivery of palliative care in China. The relationship between Chinese and Western (bio)ethics can then be further entailed by experiential evidence.

(165) Title: Organ donation after euthanasia, morally acceptable under strict procedural safeguards

Authors: Gert van Dijk, Department of Medical Ethics, Erasmus Medical Center Rotterdam The Netherlands, Rozemarijn L van Bruchem-Visser, PhD MD, Department of Internal Medicine, Erasmus Medical Center Rotterdam, The Netherlands

Abstract:
We will present a case of organ donation after active euthanasia (ODE) in the Netherlands from a patient who had his life ended at his explicit and voluntary request. The form of ODE we will describe concerns patients who are not unconscious and on life support, but who are conscious and want to have their life ended because of their hopeless and unbearable suffering, for instance due to a terminal illness such as Amyotrophic Lateral Sclerosis (ALS) or Multiple Sclerosis (MS). This form of ODE is of course only possible in jurisdictions where euthanasia is allowed. In these jurisdictions, organ donation after euthanasia is an option that may be considered. We believe ODE is worthwhile to pursue, as it can strengthen patient autonomy, can give meaning to the inevitable death of the patient, and be an extra source of much needed donor organs. To ensure voluntariness of both euthanasia and organ donation and avoid conflict of interest by physicians, ODE does need strict procedural safeguards however. The most important safeguard is a strict separation be-tween the 2 procedures. We will discusses several ethical issues such as who should broach the subject of organ donation and who should perform the euthanasia, and how a conflict of interest can be avoided.

(166) Title: Urban public health ethics: a research agenda

Authors: Cristian Timmermann; Dr. - research associate; Ethics of Medicine, Medical Faculty, University of Augsburg

Abstract:
Depending on how cities are planned and allowed to grow, they can either foster or deteriorate the health of their dwellers. Access to green areas has a positive effect on mental health, bike lanes can lead to regular exercise while commuting, squares acts as points of encounter thereby reducing solitude, and sidewalk trees improve thermal comfort. Conversely, lack of vegetation converts cities in heat islands, car dependence leads to a sedentary lifestyle and deteriorates air quality, and insufficient meeting points without consumption obligation make it difficult for people with low purchasing power to socialize.
From a public health ethics perspective, we should not concentrate on whether some individuals manage to lead healthy lives despite unfavourable conditions. We should rather be concerned whether certain forms of urban planning facilitate or impede healthy lifestyles and if so, for whom.
On basis of a literature review and an ethical analysis we proceed in three stages.
First, we defend the sufficient availability of health promoting infrastructure for all. As health is such a broad concept and there are so many factors that promote health, it is impossible to narrow down the responsibilities to provide a health promoting infrastructure to a single institution. Health promotion needs to be defended as a goal within the design of shared infrastructure and thereby become a common task.
Second, we argue for everyone having the opportunity to live and gather the necessities for a good life without ending up harming the health of others. As the risks of new pandemics increase with climate change and older pathogens adapt, it becomes crucial that people are able to live fulfilling lives while maintaining the risk of being a disease vector low, which demands sanitary systems and shelters of sufficient size to avoid overcrowding.
Third, we assess in how far we need to respond to reasonable expectations to maintain the status quo. Some people have made considerable investments in improving their well-being, by building houses in hard to reach suburban areas or getting comfortable cars as their main means of transportation.

(167) Title: When persuasion, interpersonal leverage and inducements become coercive: A context-sensitive model of informal coercion in psychiatry

Authors: Christin Hempeler, Medical Doctorate Student, Institute for Medical Ethics and History of Medicine, Ruhr-University Bochum - contribution: development of idea, structure, argumentation and case examples

Abstract:
The use of coercion in the treatment of people with mental illness raises important ethical challenges. In the context of psychiatry, two broad categories of coercion can be differentiated. Formal coercion involves interventions such as involuntary commitment, involuntary medication or seclusion. These are exerted against the will of service users and without their consent. Informal coercion, on the other hand, refers to communicative strategies used to influence the decisions and behavior of service users to obtain consent and improve their adherence to recommended treatment or social rules.
Although informal coercion is ubiquitous in the everyday life of service users, it is neither conceptually clear nor sufficiently represented in empirical psychiatric research. The most influential conceptualization of this phenomenon proposed by Szmukler and Applebaum describes a hierarchy of communicative strategies with increasing pressure. These include persuasion, interpersonal leverage, offers and threats. Their conceptualization is built on classical philosophical baseline approaches to coercion and follows their thesis that only threats coerce while offers and other forms of psychological pressure do not.
I argue that baseline approaches and, as a consequence, the predominant conception of informal coercion are insufficient within the context of psychiatry. They are insufficient because they focus solely on the content of proposals and fail to take the context in which these proposals are made into account. I identify a fundamental power imbalance between professionals and service users as a relevant context factor in mental healthcare. In analyzing a series of examples drawn from the clinical context, I show how this power imbalance can manifest in a) the possibility of formal coercion or b) a dependency of service users on professionals. I argue that in presence of these contextual factors, persuasion, interpersonal leverage and offers can create the justified perception of an underlying threat and can thus be coercive.

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Conclusions

In Bioethics, enhancing dialogue can certainly help to bridge gaps.
Among many, I would like to stress two important characteristics of dialogue:
Dialogue is like a bridge because it is inclusive: it does not ignore diversities but offers the chance to stand up and talk. It allows to overcome and go beyond their appearance, often in surprising ways.
Dialogue is a bridge because it outlines the interdisciplinarity: the philosopher who does not know about medicine allows the physician to be a better physician; at the same time, the physician who does not know about philosophy, allows the philosopher to be a better philosopher.
This is something we have seen and felt during these days and that makes the future promising.

In a few minutes you will receive a small gift: it's a mug with our university logo.
We wish this mug will recall you our University and Varese when back home.
This mug is a symbol of a continuous dialogue because you can use it daily during short moments shared with colleagues and friends like coffee break or lunch: we all know these are often precious moments to talk and imagine future paths for bioethics.
This mug also gives me the opportunity to say thank you:
thanks to everybody, thanks to the Bureau,
thanks to the organizing agency,
and a special thanks to Federico, Elena and Alessandra and to all my PhD students.

Prof. Mario Picozzi