EACME
EUROPEAN ASSOCIATION
OF CENTRES OF MEDICAL ETHICS

Translating Ethics into Healthcare Practice and Research.
Potentials and Risks

EACME 2024

ANNUAL CONFERENCE

12–14 SEPTEMBER, HALLE/SAALE (GERMANY)

PROGRAMME & ABSTRACTS

EACME EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

PZG Profilzentrum Gesundheitswissenschaften

Medizinische Fakultät der Martin-Luther-Universität Halle-Wittenberg

UKH Universitätsklinikum Halle (Saale)

supported by

hallesaale HÄNDELSTADT

VERSION: 4th OF SEPTEMBER

Please note that any short notice changes will be indicated at the registration desk.

CONTENT

Welcome to EACME 24 in Halle/Saale

We would like to welcome you to EACME 24 in Halle/Saale.

With about 170 submissions from researchers of more than 20 countries we are grateful for the positive response to this year's call for abstract. We now look forward to an interesting conference and wish all participants fruitful sessions and an interesting and memorable time at EACME 24 in Halle/Saale.

Conference Topic

Translating ethical norms and values into healthcare practice, research and public health has received considerable attention in recent years. While the concept of "translation" has been used rather heterogeneously in the bioethics discourse, there seems to be a shared underlying notion that it is not enough to formulate ethical norms or values for them to have an impact in and on healthcare.

The general idea of translating ethics into healthcare seems to be attractive – not only for researchers in bioethics but also for funding organizations and the different professions working in healthcare and research. However, there are conceptual, methodological, and practical challenges. On a more fundamental level it is not undisputed whether a sound concept of translation of ethics is possible (e.g., in analogy to the elaborated concepts in translational medicine). Even if we may agree on this possibility, it is debatable whether translational studies are a task for researchers in bioethics or rather for experts from other disciplines. This raises questions regarding the disciplinary expertise needed for translating ethics. Furthermore, there have been few translational studies published so far which could serve as illustrating example for translating ethics into healthcare or research. Finally, one might also wonder whether there are risks associated with translating ethics into healthcare. Such negative consequences could be envisaged for both the field of bioethics and for healthcare practice and research.

Against this background we are looking forward to explore conceptual foundations, methodological challenges as well as practice examples which deal with translating ethics with scientists from numerous disciplines at EACME 24 in Halle/Saale.

The conference team of EACME 24 looks forward to welcoming you in Halle/Saale.

On behalf of the EACME 24 conference team

Jan Schildmann

THANK YOU

Thank You

For their support in preparing the annual conference, the conference organizers would like to thank in particular the members of the scientific committee, Angelique Heijnen, Ruth Horn and the EACME Bureau. We would like to thank the City of Halle/Saale for the financial support.
Thanks also go to the local organizing committee in Halle/Saale and Ms Vach and the team from CONVENTUS. Finally, we would like to thank all the invited speakers and all those who submitted a contribution.

Scientific Committee

Ana Borovecki, Zagreb
Jean-Philippe Cobbaut, Lille
Chris Gastmans, Leuven
Ruth Horn, Augsburg
Richard Huxtable, Bristol
Patrick Jahn, Halle/Saale
Pawel Lukow, Warsaw
Bert Molewijk, Amsterdam
Federico Nicoli, Varese
Henning Rosenau, Halle/Saale
Rouven Porz, Bern
Carola Seifart, Marburg
Sebastian Wäscher, Zurich

Organizing Committee Halle/Saale

Jan Schildmann (Chair)
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Emilia Droese
Christian König
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Rebecca Martin
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Theresa Schneider
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Anne Wanke

IMPORTANT NOTE!

Film and sound recordings as well as photos will be made at the event.
By attending the event, you agree that these recordings may be used in the public space – for example on the intranet, the online portal, the social media channels and in radio, TV and print media (including books).

Website
Eacme2024.org

Traveling to Halle/Saale
Halle has favourable IC and ICE transport connections. There are also motorway connections to the A9, A14, A38 and A 143 motorways as well as connections to the B6, B71, B80, B91 and B100 federal roads.

Leipzig-Halle Airport is located halfway between the two major cities and has a direct motorway connection (A9/A14). In addition, the Deutsche Bahn Airport Express runs hourly to/from Halle and Leipzig.
The journey from Berlin Airport takes around 3 hours and is available approximately every 30 minutes.

Venue (see Map Venue on page 119)
Martin-Luther-Universität Halle-Wittenberg I Löwengebäude & Melanchthonianum (Martin-Luther-Universität Löwengebäude – Google Maps)
Universitätsplatz 9 I 06108 Halle/Saale

You can reach the Universitätsplatz on foot from the main railway station in approx. 25 minutes.

Directions: Tram lines 2, 5 and 7 will take you to Universitätsplatz
Please get off at one of the following stops:
– Joliot-Curie-Platz: Lines 2 and 5
– Marktplatz: Line 2 and 5
– Neues Theater: Line 7

When you arrive at Halle/Saale main station, the above lines run from two departure points.
Tram lines 2 (direction 'Soltauer Straße') and 5 (direction 'Kröllwitz') depart from platform C at the 'Hauptbahnhof' stop at the Ernst-Kamieth-Straße exit (about 100 metres from the station building, accessible via a lift).You can use these to get to either the 'Joliot-Curie-Platz' or 'Marktplatz' stop. From there it is about 450 metres to the venue. From 'Joliot-Curie-Platz', walk in the direction of the tram for approx. 200 m along Große Steinstraße, then turn right into Barfüßerstraße. Walk straight ahead for 400 metres, cross the small intersection and finally reach Universitätsplatz via the pedestrian ramp. From the 'Marktplatz' stop, turn into Kleinschmieden, then right into Große Steinstraße, after approx. 70 metres turn left into Barfüßerstraße and continue as described above.
Tram line 7 (direction 'Kröllwitz') departs from the Hauptbahnhof stop at the Hans-Dietrich-Genscher-Platz exit on platform A and is barrier-free. You will reach the stop after crossing the station forecourt. Take line 7 to the 'Neues Theater' stop. This is approx. 250 metres from the Löwengebäude/ Melanchthonianum. From there, walk 70 metres in the direction of the tram along Große Ulrichstraße, turn right into Schulstraße and after about 100 metres turn left into Universitätsplatz.

THE CITY OF HALLE, CULTURE AND CONFERENCE DINNER

The conference dinner will take place on 13.9.2024, from 20:00 and can be booked with the congress registration.

Restaurant Speiseberg
Bergschenke
Kröllwitzer Straße 45
06120 Halle (Saale)
https://bergschenke-halle.com/

A guided tour through the Meckelsche Sammlungen
of the Institute of Anatomy and Cell Biology of the
Martin Luther University Halle-Wittenberg will take place
on 12.9.2024, 12:30–13:30 and 19:00–20:00.
Due to the limited number of people, prior registration is
required for the guided tour as part of the congress registration.

The *Meckelsche Sammlungen* of the Institute of Anatomy and Cell Biology at the Martin Luther University Halle-Wittenberg are among the top ten anatomical and pathological collections in Europe. They contain around 8,000 medical and zoological exhibits, including unique and extremely valuable medical-historical specimens dating back to the 18th century. At the heart are the specimens from the Meckel collection of the famous Meckel family of doctors. In 2015, the anatomical teaching and research collection was added to the list of "National wertvolles Kulturgut" (cultural property of national significance).

A guided tour through Halle will take place
on 12.09.2024, 12:30–13:30.
Due to the limited number of people, prior registration is required for the guided tour as part of the congress registration.

On the **Halle City Tour**, you get to know the most important sites in Halle's immediate city center with its history. Walk past the birthplace of George Frideric Handel (Handel House). Take a look at the market ensemble with its five towers and experience Halle's market square that is one of the most beautiful in Germany. The city guide will introduce you to exciting and interesting facts about Halle.

Meeting point for guided tours (social programme):

Meckel Collection	first tour 12.9., 12.20 hrs	In front of the building of the Institute for Anatomy, Große Steinstraße 52
Meckel Collection	second tour 12.9., 18.30 hrs	in front of "Löwengebäude", Universitätsplatz 11
City Tour	12.9., 12.20 hrs	in front of "Löwengebäude", Universitätsplatz 11

PLENARY SESSIONS AULA (LÖWENGEBÄUDE)

12.09.2024 **Opening & Plenary I 14.30–16.20**
14.30–14.50 **Opening**
The conference registration opens at 1 pm at the main university building („Löwengebäude“) Universitätsplatz 11.

14.50–16.20 **Plenary Session I Translating Ethics into Healthcare. Conceptual and Methodological Aspects**
Marcel Mertz, Hannover
Kristine Bærøe, Oslo

Get Together I 18.30

13.09.2024 **Prize & Plenary I 09.00–10.50**
09.00–09.20 Announcement of EACME Prizes
- The Paul Schotsmans Prize for young talented scholars (i.e. PhD students)
- The EACME Visiting Scholarship Exchange Award
- The EACME Collaboration Awards

09.20–10.50 **Plenary Session II Translating Ethics into Health Policies**
Michael Parker, Oxford
Scott Kim, Bethesda

Plenary, Announcement I 16.00–17.40
16.00–17.30 **Plenary Session III Translating Ethics into Clinical Practice**
Ellen Fox, Washington
Georg Marckmann, Munich

17.30–17.40 **Announcement BENE-Bioethics Education Network Europe** (Yesim Isil Ulman, Rouven Porz)

EACME General Assembly & EACME board elections (for members) I 17.45-19.00

14.09.2024 **Plenary & Closing I 11.00–12.45**
11.00 **Plenary Session IV Participation as a Route to Translation in Ethics**
Jonathan Ives, Bristol
Katja Kuehlmeyer, Munich

12.30 **Closing of Conference**

Moderation Plenary Sessions

Plenary I	Chairs: Metselaar/Schildmann
Plenary II	Chairs: Winkler/Schildmann
Plenary III	Chairs: Porz/Schildmann
Plenary IV	Chairs: Salloch/Schildmann

Opening & Plenary | 14.30–16.20

14.30–14.50 **Opening**

14.50–16.20 **Plenary Session I Translating Ethics into Healthcare. Conceptual and Methodological Aspects**
Marcel Mertz, Hannover
Kristine Bærøe, Oslo

Parallel Session I | 16.45–18.15

1.1 SHORT PRESENTATION I LH Z	SESSION 1.2 LH B	SESSION 1.3 LH A	SESSION 1.4 LH XII	SESSION 1.5 LH XIII	SESSION 1.6 LH XIVc
Chair: Horn	**Chair: Wäscher**	**Chair: Aluas**	**Chair: Huxtable**	**Chair: Pegoraro**	**Chair: Inthorn**
1.1.1 Richter How to elucidate consent-free research use of medical data: a case for „health data literacy“	**1.2.1 Sheehan** Mistranslations: The Uses and Abuses of Deliberative Democratic Methods	**1.3.1 Molewijk** Avoiding right and wrong: Using a non-normative dialogical ethics support and action research for a normative aim: fostering psychosocial safety	**1.4.1 Locke** Cultural Complications of Translating Healthcare Ethics	**1.5.1 Jungkunz** Bridging the gap between theory and practice: development and implementation of ethical policies for translational genomic research	**1.6.1 Schweer** The Gap Between Theory and Practice: Blurring Boundaries of Current Consent Approaches in Health Research Practice
1.1.2 Zimmermann Approaches and challenges of teaching research ethics to biomedical science undergraduates	**1.2.2 Kremling** „From book to bedside?“ or: Alternatives to drawing an ethical analogy to translational medicine?	**1.3.2 Knochel** Preparing ICU teams for triage during a pandemic: About transdisciplinary development, implementation, and research	**1.4.2 Zhao** Translation of Bioethics Across Cultural Borders: Exploring the Adoption of the Four-Principles Approach in Chinese Contexts	**1.5.2 Ambrosj** Codes of Conduct Should Help (Biomedical) Scientists Navigate Societal Expectations	**1.6.2 Ihle-Hansen** Patient preferences in geriatric wards, a survey of health care professionals‘ practice, experience and attitudes
1.1.3 Gloeckler The Ethical Use of Augmented and Virtual Reality in Mental Health Services	**1.2.3 Minari** The Need for Reverse-Translational Bioethics in Health Research and Healthcare Practice	**1.3.3 Reato** At Home Ethnography and Interviews to the Double for the construction of the Repertoire of Core Competencies of the Clinical Ethics Consultant in the light of the European and Italian Qualifications Framework	**1.4.3 Le Berre** Mourning of spouses after deep and continuous sedation until death: ethical issues of a dialogue between medicine and society, in the french context	**1.5.3 Fluck** Post-trial care in gene therapy clinical trials: ethical implications and their potential impacts on scientific research	**1.6.3 Kuiter** Should healthcare professionals include aspects of environmental sustainability in clinical decision-making? A systematic review of reasons
1.1.4 Pirson The prospect of direct benefit in first-in-human gene therapy studies in minors: an ethical analysis	**1.2.4 Mertz** „Full“ health technology assessment (HTA) reports as a device for „translating“ ethics into healthcare practice: observations on the suitability, implementation and reach of ethics in HTA reports	**1.3.4 Dittborn** Parents and clinicians‘ experiences with remote paediatric clinical ethics consultation during the pandemic: A service evaluation	**1.4.4 Alex** Interdisciplinarity in bioethics and associated challenges	**1.5.4 Al** An ethical argument to limit financial incentives to clinical trial participants	**1.6.4 Kupsch** Assessment of decisional capacity: A systematic review and analysis of instruments regarding their applicability to requests for assisted suicide

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session I | 16.45–18.15

1.1 SHORT PRESENTATION I LH Z	SESSION 1.2 LH B	SESSION 1.3 LH A	SESSION 1.4 LH XII	SESSION 1.5 LH XIII	SESSION 1.6 LH XIVc
Chair: Horn	**Chair: Wäscher**	**Chair: Aluas**	**Chair: Huxtable**	**Chair: Pegoraro**	**Chair: Inthorn**
1.1.5 Schmieg Ethical Guidance in Case Management: A Translational Approach to Support Caregivers and Patients with Chronic Conditions in Palliative Care to prevent ‚Moral Distress' and ‚Moral Injury'					
1.1.6 Hirose Misuse of ethical terminology reduces trust in vaccines: A case of HPV vaccines in Japan					
1.1.7 Birchley Emotion, rationality and ethics in „best interests" decision-making: addressing the Apollonian and Dionysian divide					

Reception | 18.30

Löwengebäude

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Prize & Plenary | 09.00–10.50

09.00–09.20 **Announcement of EACME Prizes**

09.20–10.50 **Plenary Session II Translating Ethics into Health Policies**
Michael Parker, Oxford
Scott Kim, Bethesda

Parallel Session II | 11.15–12.45

2.1 SHORT PRESENTATION II LH Z	SESSION 2.2 LH B	SESSION 2.3 LH A	SESSION 2.4 LH XII	SESSION 2.5 LH XIII	SESSION 2.6 LH XIVc
Chair: Nadolny	**Chair: Sommerlatte**	**Chair: Izquierdo**	**Chair: Łuków**	**Chair: Molewijk**	**Chair: Nicoli**
2.1.1 Inguaggiato Virtue ethics as a tool for translational ethics. A plea for the use of a virtue ethics approach in clinical ethics support services	**2.2.1 Spagnolo** Parkinson's disease patients with Deep Brain Stimulation (DBS): A qualitative exploration of evolving experiences over time	**2.3.1 Kraft** Ethical competencies for digitally supported care	**2.4.1 Maas** Paediatric informed consent procedures: A potential clinical application for Large Language Models?	**2.5.1 Burmeister** Decision-making & diversity: The limits of Standardized Deliberation in healthcare facilities	**2.6.1 Horn** Negotiating severity behind the scenes: prenatal testing in Germany
2.1.2 Stange Revealing ideas of the good life in the context of creating advance directives: A qualitative approach	**2.2.2 Cassinadri** Non-voluntary BCI Explantation: Assessing Possible Neurorights Violations in Light of Embedded and Extended Cognition	**2.3.2 Kuehlmeyer** Translating ethics into practice through competency-oriented teaching and learning: Experiences from the German KOMETH-Learn project	**2.4.2 Buhr** Use of AI in psychiatry - ethical challenges in theory and practice	**2.5.2 Gothan** Decision-Making in Gender Affirming Medical Care/Surgery (GAMC/GAS): A Systematic Review and Ethical Evaluation of Guideline Recommendations	**2.6.2 Dierickx** Creating ethics guideline for cancer care during pregnancy: work in progress
2.1.3 Esquerda Aresté Ethical considerations in psychiatric euthanasia	**2.2.3 Starke** Hybrid Minds: Experiential and ethical implications of intelligent neural interfaces	**2.3.3 Radvanszky** Translation of qualitative interviews: Implementing patient narratives in medical education. Examples from DIPEx Switzerland	**2.4.3 Willem** Embedded Ethics in Practice: A Toolbox for Integrating the Analysis of Ethical and Social Issues into Healthcare AI Research	**2.5.3 Ellerich-Groppe** Queering healthcare with digital technologies: How the digital transformation can contribute to diversity- and queer-sensitive healthcare	**2.6.3 Gregorowius** Mentally ill Women with a Desire to have Children: How Translational Ethics can help to develop Instruments for Preconception Counselling
2.1.4 Karneboge Project ESDA: Evaluation of Supported Decision-Making Strategies for Monoclonal Anti-Beta-Amyloid Antibodies	**2.2.4 Vassallo** Assessing Cognitive Enhancement	**2.3.4 Dierickx** Do we achieve anything by teaching research ethics to starting PhD students?	**2.4.4 Rudra** Leveraging AI-Based Chatbots to Enhance Patient Consent in Healthcare: A Digital Ethical Perspective	**2.5.4 Cutas** What kind of ties are genetic ties and why does it matter?	**2.6.4 Zuijderland** Between Existence and Essence: The ‚Liminal Being' and ‚Sublime Child' in Abortion Ethics
2.1.5 Jungkunz Hospitals as moral actors with institutional duties					

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session II | 11.15–12.45

3.1 SHORT PRESENTATION III LH Z	SESSION 3.2 LH B	SESSION 3.3 LH A	SESSION 3.4 LH XII	SESSION 3.5 LH XIII	SESSION 3.6 LH XIVc
Chair: Nadolny	**Chair: Sommerlatte**	**Chair: Izquierdo**	**Chair: Łuków**	**Chair: Molewijk**	**Chair: Nicoli**
2.1.6 Mori Japanese Public Medical Insurance System in Crisis					
2.1.7 Kelam Overview of Ethical Education Among Healthcare Workers in Croatia					

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session III | 14.00–15.30

3.1 SHORT PRESENTATION III LH Z	SESSION 3.2 LH B	SESSION 3.3 LH A	SESSION 3.4 LH XII	SESSION 3.5 LH XIII	SESSION 3.6 LH XIVc
Chair: Fuchs	**Chair: Kremling**	**Chair: Esquerda Aresté**	**Chair: Vogel**	**Chair: Trachsel**	**Chair: Sacchini**
3.1.1 Schmieg Ethical Navigation in Rare Disease Care: Understanding and Acting on Parents' Insights to Improve Quality of Life	**3.2.1 Krawczyk** Meaningful Inclusion? Influence of Research Institutions on Epistemic Injustice within Patient and Public Involvement	**3.3.1 García-Calderó** Loneliness and solitude experiences of adolescents and young adults during the COVID-19 pandemic: a qualitative systematic review	**3.4.1 Fasoli** Emerging Technologies and Vulnerabilities in Older Adults without Cognitive Impairments: a Systematic Review of Qualitative Evidence	**3.5.1 Huxtable** Orchestrating Best Interests Decision-Making: A Qualitative Study of Best Interests Decision-Making in Healthcare in England and Wales	**3.6.1 Ariffin** Exploring the Experience and Perspective of Practice, Teaching and Learning of ‚Informed Consent' in the Malaysian Clinical Settings: A Qualitative Study
3.1.2 Terribas The experience of euthanasia in Spain: figures and difficulties of application	**3.2.2 Nadler** Empowering patient voices: Shaping ethical digital health research together through a collaborative discourse at a stakeholder-conference	**3.3.2 Buchberger** Professional ethos under pressure: what internal tensions did healthcare workers have to face during the COVID-19 pandemic? Results of a qualitative study with detailed insights into ethical and individual challenges	**3.4.2 Nebowsky** Care Across Borders: A Practice Oriented Analysis of Vulnerabilities in Migrant Live-in Home Care for Persons with Dementia in Germany and Israel	**3.5.2 Le Berre** Support for family caregivers in Day Hospital in palliative care: vulnerability and power of grief	**3.6.2 Wienmeister** How about a (tiny) little bit of informal logic? Promoting moral reasoning skills in students through argumentation theory as a means to translate ethics into healthcare practice
3.1.3 Hirsch Practicing ethical discourse as a means of translating ethics into healthcare practice: Experiences from a participatory teaching project on biomedical enhancement	**3.2.3 Ceruti** The introduction of Research Ethics Consultation Services in Italy: Theoretical-practical reasons supporting the adoption of a co-operative-collaborative approach to ethical issues raised by clinical research	**3.3.3 Kavas** Moral Injury Experiences and Perceptions of Self as a Moral Subject of Healthcare Workers Working in and behind the Field in the Earthquakes of February 6, 2023 in Türkiye: Developing Quality Criteria and Solution Suggestions for Moral Resilience	**3.4.3 Aleksandrova-Yankulovska** Qualitative research in support of empowering participation of children in SIRS research	**3.5.3 Parsons** Best Interests and Rotten Compromise: exploring the instrumentalisation of P	**3.6.3 Steindorff** Embodiment as a resource for person-centred and ethical value-based care in the light of VR-supported nursing training
3.1.4 Verbeke Contributing to a more Coherent and Comprehensive Understanding of the Research Ethics of Deception: an Interview Study with Researchers	**3.2.4 Potthoff** Qualitative health research under ethical review. A comparison between review practice and interventions for improvement by applicants and members of medical research ethics committees in Germany		**3.4.4 Vinogradova** Nursing homes in times of a pandemic: to close or not to close? Reflections on restriction measures during the COVID-19	**3.5.4 Howes** One big juggling act: Developer perceptions on the ethics of tracking devices in dementia care	**3.6.4 Kiefer** Translating ethical fiduciary concepts into health research: How can data fiduciaries contribute to a trust architecture for the research use of health data?

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session III | 14.00–15.30

3.1 SHORT PRESENTATION III LH Z	SESSION 3.2 LH B	SESSION 3.3 LH A	SESSION 3.4 LH XII	SESSION 3.5 LH XIII	SESSION 3.6 LH XIVc
Chair: Fuchs	**Chair: Kremling**	**Chair: Esquerda Aresté**	**Chair: Vogel**	**Chair: Trachsel**	**Chair: Sacchini**
3.1.5 Wilken Ethical implications of integrating new technologies in clinical routine: trust and autonomy in the realm of personalised medicine					
3.1.6 Krieckemans Telehealth in palliative care settings: A systematic review of argument-based ethics literature					
3.1.7 Loute Assessing the ethical implications of using telemedicine to support patients with advanced Amyotrophic Lateral Sclerosis (ALS)					

Plenary & Announcement | 16.00–17.40

16.00–17.30 **Plenary Session III Translating Ethics into Clinical Practice**
Ellen Fox, Washington
Georg Marckmann, Munich

17.30–17.40 **Announcement BENE-Bioethics Education Network Europe (Yesim Isil Ulman, Rouven Porz)**

EACME Assembly | 17.45

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session IV | 09.00–10.30

4.1 SHORT PRESENTATION IV LH Z	SESSION 4.2 LH B	SESSION 4.3 LH A	SESSION 4.4 LH XII	SESSION 4.5 LH XIII	SESSION 4.6 LH XIVc
Chair: Neitzke	**Chair: Urbonas**	**Chair: Picozzi**	**Chair: Dierickx**	**Chair: Matejek**	**Chair: Terribas**
4.1.1 Gregorowius Translating Ethics into Action: Ensuring Advocacy, Autonomy, and Access in Disability Care	**4.2.1 Kovács** Pioneering a Novel Unified, Quantitative-Qualitative Method for Heightened Argumentative Rigor in Bioethical Dilemmas	**4.3.1 Metselaar** Translational Bioethics as a Two-Way Street. Developing Clinical Ethics Support Instruments with and for Healthcare Practitioners	**4.4.1 Spitale** WHO leads the way? Bridging ethics and practice in social listening and infodemic management	**4.5.1 Feeney** Genome Editing and non-ideal Justice: the case of Sickle Cell Disease (SCD)	**4.6.1 Langmann** Endometriosis in Later Life: An Intersectional Analysis from the Perspective of Epistemic Injustice
4.1.2 Thomas What information is important to patients with a family history of breast and ovarian cancer when giving informed consent to genetic testing?	**4.2.2 Tirschmann** Qualitative methods in participatory research and development projects for health technologies	**4.3.2 Rockmann** An argument in favour of a modified Four-Topics-Model in Ambulant Ethics Consultation	**4.4.2 Ancillotti** Development of a public health ethics framework for lighting	**4.5.2 Alex** Genomic Newborn Screening for Adult Actionable Conditions: Why Not?!	**4.6.2 Hempeler** Intersectionality as a tool for clinical ethics consultation
4.1.3 Staffa The creation of an Ethical Space within an Italian Territorial Social Health Agency to encourage community welfare	**4.2.3 Aleksandrova-Yankulovska** The role of qualitative research in translating ethics within the area of fertility protection	**4.3.3 Inthorn** Models of Clinical Ethics Consultations as translational tools. Bridging the gap between ethical expertise and clinical practice	**4.4.3 Koethemann** The concept of ethical governance and its translation into health care practice: Conceptual and empirical insights taking patient organizations as an example	**4.5.3 Ayoub** Navigating uncertainty in 22q11 deletion syndrome: how healthcare professionals balance hope and realism	**4.6.3 Davies** „Integrated“ Empirical Bioethics: Who, What, When?
4.1.4 Capulli Research involving informal caregivers of patients with dementia: challenges related to information sharing		**4.3.4 Eijkholt** Patient participation in clinical ethics interventions: Justifications and risks – an international study	**4.4.4 Katzer** Systematic, but not quality-assessed? The problem of quality appraisal in systematic reviews of reasons – and a possible solution by applying basic argumentative standards	**4.5.4 Andreoli** Taking the risk: A systematic review of ethical reasons and moral arguments in the clinical use of polygenic risk scores	**4.6.4 Timmermann** Physician's responsibilities in relation to environmental and climatic crises: A critical interpretative synthesis
4.1.5 Hattori A New Approach to Improve Clinical Ethical Competence					

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

Parallel Session IV | 09.00–10.30

4.1 SHORT PRESENTATION IV LH Z	SESSION 4.2 LH B	SESSION 4.3 LH A	SESSION 4.4 LH XII	SESSION 4.5 LH XIII	SESSION 4.6 LH XIVc
Chair: Neitzke	**Chair: Urbonas**	**Chair: Picozzi**	**Chair: Dierickx**	**Chair: Matejek**	**Chair: Terribas**
4.1.6 Sandonà Philosophical and theoretical aspects of translational bioethics					

Plenary & Closing | 11.00-12.45

11.00–12.30 **Plenary Session IV Participation as a Route to Translation in Ethics**
Jonathan Ives, Bristol
Katja Kuehlmeyer, Munich

12.30–12.45 **Closing of Conference**

Lecture Hall (LH) A, B, Z – located in Melanchthonianum; LH XII, XIII, XIVc – located in Löwengebäude

SHORT PRESENTATIONS

Please note that an additional poster for a selection of short presentations will published on the conference website.

1.1.1

Gesine Richter, University of Kiel, Institute of Experimental Medicine, Division of Biomedical Ethics, Kiel, Germany
Michael Krawczak, University of Kiel, Institute of Experimental Medicine, Division of Biomedical Ethics, Kiel, Germany

How to elucidate consent-free research use of medical data – a case for health data literacy

The extensive utilization of personal health data is one of the key success factors of modern medical research. Obtaining consent to the use of such data during clinical care, however, bears the risk of low and unequal approval rates and of consequent methodological problems in the scientific use of the data. In view of these shortcomings, and of the proven willingness of people to contribute to medical research by sharing personal health data, the paradigm of informed consent needs to be reconsidered. The European General Data Protection Regulation gives the EU member states considerable leeway with regard to permitting the research use of health data without consent. Following this approach would however require alternative offers of information that compensate for the lack of direct communication with experts during medical care. We therefore introduce the concept of "health data literacy", defined as the capacity to find, understand and evaluate information about the risks and benefits of the research use of personal health data, and to act accordingly. Specifically, health data literacy includes basic knowledge about the goals and methods of data-rich medical research, and about the possibilities and limits of data protection. Although the responsibility for developing the necessary resources lies primarily with those directly involved in data-rich medical research, improving health data literacy should ultimately be of concern to everyone interested in the success of this type of research.
The presentation begins by pointing out the urgent need to rethink the paradigm of informedness in the context of consent to interoperable and international secondary data use for research purposes. We present the concept of health data literacy as a possible solution and discuss ways for implementation aiming at translating the ethical requirement of informedness into secondary data use for health research.

1.1.2

Bettina Zimmermann, University of Bern, Institute of Philosophy, Bern, Switzerland and Technical University of Munich, TUM School of Medicine and Health, Institute of History and in Medicine, Munich, Germany

Approaches and challenges of teaching research ethics to biomedical science undergraduates

This contribution aims to reflect on how research ethics can and should be taught to medical science students to improve the translation of ethics into health research. The reflections are guided by my experiences in teaching Biomedical Sciences Bachelor students in research ethics at a Swiss university. This research ethics course includes lectures from multiple teachers coming from science and ethics. Originally conceptualized as a traditional lecture course including a multiple choice exam and some limited interactive elements, I describe the development of the course into an interactive experience. Using this course as a case study, I reflect on three aspects of teaching research ethics to science students. First, I discuss the necessary and appropriate learning outcomes. I will argue that undergraduate science students, above all, need to experience what ethical reflection and reasoning entails since this line of thinking is different from their scientific training. Second, I will assess the appropriate teaching and evaluation strategies to achieve such an outcome, advocating for an interdisciplinary setup of such classes, interactive teaching methods, and evaluation strategies that allow students to engage in ethical reasoning. Third, I will outline potential obstacles and challenges to these approaches. I will close by discussing the relevance of such research ethics courses in translating ethics into health research.

1.1.3

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Nikola Biller-Andorno, University of Zurich, Institute for Biomedical Ethics and History of Med, Zurich, Switzerland

The Ethical Use of Augmented and Virtual Reality in Mental Health Services

Question: New innovations in virtual and augmented reality technology are likely to impact the delivery of health services, including mental health services. The ability to monitor and modulate intimate physiological experiences with these technologies makes them powerful tools for enhancing existing treatment modalities, but also demands careful attention to possible violations of mental integrity and privacy. What early interventions can be identified that, if implemented into practice, might help mitigate the potential ethical concerns of using virtual and augmented reality when providing mental health services? Methods: In 2023, an e-Delphi study was conducted with 14 global clinical and academic experts to explore their views on the Metaverse as a setting for the provision of appropriate mental health services. The present work further develops a subset of those findings through literature review and expert consultation to refine an understanding of early best practice for safeguards that might support the ethical use of virtual and augmented reality in the provision of mental health services. Results: A few key interventions were identified that should be further explored and developed. These include careful limitations and informed consent around the gathering and storing of tracking data; transparency regarding who is involved in providing a service and what the associated costs are; AI-conversational agents and/or product placements that are visually distinct and easily identifiable; necessary involvement of clinicians in the delivery of some services; and service user input to inform development and design. Conclusion: Mental health clinicians have long recognized that powerfully effective interventions also often carry serious risks. If virtual and augmented reality have the potential to significantly enhance current treatment modalities for certain mental health conditions, early efforts must be made to recognize how best to use these tools ethically and responsibly so that they do more good than harm. Elements to attend to include both the more technical questions, for example regarding proper use of data, and the more psychological, for example regarding the integrity of the sense that our beliefs and actions come from ourself.

1.1.4

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The prospect of direct benefit in first-in-human gene therapy studies in minors – an ethical analysis

Guidelines and policies play an important role in translating ethics into health research and healthcare practice. For instance, guidelines governing the initiation and conduct of translational clinical trials for novel therapies contain implicit and explicit normative views on the conditions under which such research is permissible. In this research, we investigate how ethics are translated through guidance in the context of first-in-human pediatric gene therapy trials. Recent developments in gene transfer and gene editing hugely facilitated therapeutic advances in the treatment of monogenetic pediatric diseases. First-in-human (FIH) trials are a crucial step towards market authorization. Such trials involve notable uncertainties and risks, and for diseases that manifest in early childhood adult data are often lacking. In research involving minors, an important requirement in many guidelines to allow exposure to more than minimal risks is that there must be a prospect of direct benefit for the minors involved. However, in FIH pediatric gene therapy trials it can be questioned whether a certain therapy meets this requirement for a prospect of direct benefit and when such trials should be allowed, due to the uncertainty that accompanies them. To aid the review of these trials, we investigated definitions of the prospect of direct benefit in the ethical literature and important guidelines and policies, such as the European Clinical Trial Regulation, FDA Common Rule and CIOMS guidelines. Additionally, we explored if and how preclinical research can substantiate evidence for the prospect of direct benefit.We found that "benefit" is inconsistently defined, allowing different types of benefit to influence risk-benefit analysis. In some regulatory guidelines, direct benefit solely refers to clinical benefits that result from an intervention, whereas other guidelines also include other, indirect, benefits in their definition of direct benefit. In addition, we found that what is meant with "prospect" is ill-defined in many regulatory guidelines. This raises questions on how this requirement for a "prospect" of direct benefit needs to be interpreted. We provide recommendations how this prospect could be understood. To do so, we look at different types of evidence - mechanical and statistical - that are used to substantiate claims of effectiveness, and thus potential direct benefit. Clearly defining and accurately interpreting the requirement and notion of a prospect of direct benefit is crucial for effectively reviewing FIH pediatric gene therapy trials to ensure that translation of much needed research happens in an ethical way. A failure to do so could lead to mislabeling trials as providing a prospect of direct benefit, fostering therapeutic misconception and accepting trials with an unfavourable risk-benefit ratio.

1.1.5

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Ethical Guidance in Case Management: A Translational Approach to Support Caregivers and Patients with Chronic Conditions in Palliative Care to prevent 'Moral Distress' and 'Moral Injury'

Background

Providing Palliative Care to chronically ill patients with a focus on alleviating suffering and improving quality of life at the end of life is a major challenge for both, those affected as well as the treatment team. On the shared care journey, professionals are often confronted with profound ethical questions and dilemmas that can lead to 'moral distress' and 'moral injury'. They often arise when there is disagreement between what is perceived to be the right path and the path actually taken. Both, 'moral distress' and 'moral injury' and are important reasons for dissatisfaction, burnout, and resignations among professionals and thus are examples of ethical concepts recognized in healthcare. They are thus examples of the link between medical ethics and empirical social sciences used in the sense of transitional ethics in healthcare practise.

Aim

The aim of ethical guidance is to strengthen resilience and reduce the occurrence of 'moral distress' and 'moral injury', which also improves the quality of care for the patients directly affected. So far, no systematic overview on tools, concepts, techniques, and strategies exists that can help professionals in healthcare to prevent 'moral distress' and 'moral injury'.

Methods

Based on a literature review on 'moral distress' and the results of previous evaluation projects in medical decision-making carried out by the authors, various tools, concepts, and strategies to help professionals in healthcare were identified and summarized in a list called "ethical backpack". This 'ethical backpack contains various tools and concepts that can be used by the care team to identify conflicts of values and to support decision-making in Palliative Care. The patient's well-being is the primary focus here. However, equally important are the strategies and techniques for self-care and for building resilience, as well as the opportunity to pause for a moment along the way and, with an external perspective, for example using ethical moderation, to clarify the current position and the next steps and to promote communication skills in the team through ethical reflection.

Results

The metaphor of the "ethical backpack", equipped with these essential tools and resources, illustrates how Palliative Care professionals can prepare for their demanding and often stressful task and request support. It emphasises the importance of knowledge, self-awareness, emotional intelligence, and personal care in a field that is both professionally and emotionally demanding. It helps both the treatment team and those affected and their relatives to plan in advance and to counteract stress factors in the event of uncertainties, conflicts and unexpected crossroads.

Conclusion

Early ethical guidance can help to reduce 'moral distress' and 'moral injury' in the context of palliative care and promote the well-being of affected patients and the treatment team alike. This process enables professionals to focus on the values that are important to patients and their relatives in addition to their medical expertise and thus experience meaningfulness in their own actions.

1.1.6

Kazutaka Hirose, Kyoto Prefectural University of Medicine, Biomedical Ethics, Kyoto-city, Japan

Misuse of ethical terminology reduces trust in vaccines: A case of HPV vaccines in Japan

To what extent are governments responsible for vaccine promotion? The ethical contradictions in public health regarding human papillomavirus vaccines in Japan include a significant viewpoint from which people consider government responsibilities. This report provides a vital case study for translating public health ethics into vaccination programmes.

HPV causes several cancers, including cervical cancer, and the World Health Organization (2024) promotes the uptake of HPV vaccines. In April 2013, the Japanese Government included HPV vaccines in its National Immunisation Program. However, two months later, they suspended a proactive recommendation against HPV vaccines because of unproven side effects (Okita et al., 2020). The many news articles that had reported unproven side effects around that time influenced the Government"s decision. Subsequently, after the Government suspended the proactive recommendations, the HPV vaccination rate dropped from 70% to approximately 1% (ibid.). While the Government resumed the proactive recommendation in 2022, during the suspension period, the targeted population could receive free HPV vaccines, but the uptake rate was extremely low. This could be due to the Government"s misunderstanding regarding medical ethics.

During this period, the chairperson of the government committee explained that "it was essential to obtain a kind of informed consent" (Ministry of Health, Labor and Welfare, 2017). Was it appropriate to obtain informed consent in this case? It is true that "public justification" is important for public health ethics (Childress et al., 2002, p. 173). However, the process of gaining public trust differs from that of establishing trust between doctors and patients. The government is not a doctor, and an individual is not a patient. Subsequently, it might be difficult for healthy individuals to understand the importance of vaccines compared to the importance of medication, while the government sometimes asks the public to be vaccinated, even if some do not receive clear benefits. Moreover, the purpose of vaccines can differ from the benefits for individuals, even though they overlap. Public justification illustrates government positions that are sometimes not matched to individuals" benefits and asks individuals to understand the government"s strategies. Therefore, using "informed consent" to explain a government"s position can be misleading.

As mentioned above, the low uptake rates for HPV vaccines in Japan were affected by the Government"s position on the vaccines, which suggests that the misuse of informed consent leads to confusion and the significance of a clear understanding and the communication of public health, such as the principle of public justification. Subsequently, this report discusses an appropriate public health strategy by referring to the Japanese context of HPV vaccines.

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1.1.7

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Emotion, rationality and ethics in "best interests" decision-making: addressing the Apollonian and Dionysian divide

The dichotomy between emotional (Dionysian) and rational (Apollonian) aspects of reason have long been a source of philosophical debate and discussion. While there is some recognition in the law, bioethics and clinical practice that clinical decision-making is affected by the emotions, decision-makers commonly ignore the connection between emotion and reason. In this talk we present data from the BABEL study on best interests decision-making, gathered from interviews and focus groups with thirty-three patients, relatives, and the clinicians that treat them. The interviews and focus groups indicated that, regardless of who the decision-maker was, best interests decision-making was replete with emotion. Most participants were open about emotional influences. While a few felt comfortable with these influences, many participants problematised emotion, viewing it as a source of inconsistency or an aberrant influence on reason. This suggested that emotion was an unresolved tension within best interests decision-making.

any bioethicists recognise positive roles for emotion in ethical decisions, seeing emotions as worthy of critical reflection or as indicators of the personal salience of objective ethical principles. Equally, others espouse rationalistic models of decision-making in bioethical discourse. Both views signal putative defects of emotive reasoning: emotions are subjective, cannot be answered, and are difficult to control, and are unrepresentative of deeply reasoned values. These arguments raise important questions about the status of emotion, yet too often they are resolved by, at worst, amputating emotion from ethical reason, and at best, seeing emotions as something that can and ought to be mastered and brought into rational ethical discussion. We argue that by prioritising rationality, both approaches risks epistemic injustice towards those who are most connected to decision-making, especially those who lack the social capital to adopt a rationalising frame for their reasons. Moreover, by ignoring the socially communicative role of emotions and misconceiving the nature of moral argument as solely the preserve of objective reason, they fail to give consideration to the fundamental role of emotions in the social negotiation of morality. There is considerable empirical evidence that emotion has a multi-factoral role in cognition and behaviour, that is connected and entangled with moral reasoning. Rather than being a matter of abstract rationalisation, there is much argument in moral philosophy, underwritten by the social psychology of conformity, that suggests morality is the result of social negotiations in which emotion has an important role. Although emotion alone cannot ground valid moral judgements, the erstwhile approach of seeing emotion and moral reasoning as separate and distinguishable is flawed.

One way we might inform new bioethical approaches to accommodate such observations is to look to the use of "critical rhetorical analysis" in legal scholarship. This approach recognises that "questions over who speaks and how are they represented, who is addressed and who silenced" are fundamentally rhetorical. The force of emotion (pathos) may be appealed to as much as rationality to validate an argument. Conventionally, rhetoric is juxtaposed with rationality on the grounds that rhetoric distorts reality and manipulates emotive factors. Yet it is no less plausible to understand emotion as part of the intersubjective negotiation of social reality. One way we might begin to bridge the divide between these rationally and socially informed worldviews is to actively weigh "pathos" when making moral decisions. While we accept that pathos in itself is not a complete solution to the accommodation of the emotions, we defend our proposal as a way to acknowledge the influence of emotions and begin to consistently consider the emotional threads of ethical cases.

2.1.1

Giulia Inguaggiato, AmsterdamUMC, Ethics, Law and Humanities, Amsterdam, Netherlands
Margreet Stolper, AmsterdamUMC, Ethics, Law and Humanities, Amsterdam, Netherlands

Virtue ethics as a tool for translational ethics. A plea for the use of a virtue ethics approach in clinical ethics support services.

In the past decades, several approaches to ethics support have been developed, aiming to bring ethics reflection closer to the practice of health care and vice versa. Many of these approaches focus on the development of ethical awareness and aim to support health care professionals in facing ethically challenging situations in their daily practice. However, the questions of what it means to be a good health care professional, what defines good care, and how healthcare professionals perceive these aspects are seldom explored. In this presentation, we promote a virtue ethics approach as an additional approach to existing clinical ethics support services (CESS) for health care professionals, as a way to translate the ethics into healthcare practices.

Virtue ethics focuses on the development of moral characters that allow an individual to express excellent behaviors. It provides a framework to reflect on what are the characteristics that make an excellent caregiver (virtues) and how they can be embodied in everyday practices, especially in morally challenging situations. By acknowledging the moral ambiguity implicit in ethical dilemmas and questions, virtue ethics supports professionals in reflecting on what type of professionals do they want to be, what the ultimate goals of their profession are, and what qualities professionals should have to support these goals. In doing so, it explores the relationship between personal motivations and ethical conduct, and builds a bridge between individual moral compasses and (ethical) standards or professional guidelines that support the practice of healthcare.

Based on our experience in the field of research integrity, we argue that establishing CESS inspired by virtue ethics can add to the existing practices by providing tools and methods to supports healthcare professionals in reflecting on their personal and professional development while providing support in dealing with concrete dilemmas they experience. We illustrate this with examples of methods and exercises originally developed for the field of research integrity and adapted for the context of health care.

2.1.2

Lena Stange, University of Oldenburg, Department of Health Services Research, Ethics in Medicine, Oldenburg, Germany

Revealing ideas of the good life in the context of creating advance directives - A qualitative approach

Question

Advance directives are legally protected as an expression of the author's self-determined will regarding their medical treatment in case they are no longer able to make decisions for themselves. So far, ethical debates primarily address the *formal* structure and legal validity of advance directives whereas questions regarding their *contents*, such as personal motives and often implicit ideals of life and death, are scarcely considered. However, various ethical questions are involved here: What significance do ideas of health, aging and dying have for advance directives? What values and wishes matter when planning future healthcare? This demands a qualitative approach that allows a closer look at underlying conceptions and values regarding (later) life and dying to find out to what extent these conceptions and values are well-considered and consistent with the will expressed in an advance directive. As ways of living and dying are as varied as life itself, they are addressed, experienced, suppressed and presented in a variety of ways. However, people are often not aware of their most fundamental values and convictions and their practical implications for advance directives. How can such teleological relevant aspects be explored?

Methods

To gain empirical knowledge about the abovementioned matter, qualitative interviews about life plans, experiences and ideas regarding life, health, illness and dying were conducted with 18 individuals in four age groups. These perspectives were analysed from the perspective of an ethics of the good life with regard to the coherence and potential discrepancies between personal values and the will expressed in the advance directive. Reflexive thematic analysis was used to disclose underlying conceptions of life, dying and death that influence the individuals" views on later life. Reflexive thematic analysis allows, simultaneously and equivalently, to examine manifest as well as latent content in order to identify guiding themes and concepts. Thus, this is an appropriate method to identify hidden aspects and implications that have considerable teleological weight, especially regarding personal orientations and individual impetus with regard to future life phases.

Results

Some interviewees express values and wishes regarding later life, but no explicit plans. This indicates that self-determination does not automatically lead to the capacity to phrase congruent plans in line with an advance directive. Moreover, people are often not aware of their most fundamental convictions and their practical implications for advance directives. From the perspective of a teleological ethics of the good life, this is highly relevant as personal orientations for future life phases touch upon questions of people"s awareness of what they are striving for: what they want and what they should want.

Conclusions

The consideration of individual values and wishes that motivate engagement in advance directives is highly relevant for medical ethics and health policy and contributes to the ongoing discourse about the impact and constraints of advance directives. This points to the necessity of appropriate methods to approach issues in medical ethics such as the understanding of underlying concepts of a good life in the expression of patients" wills - and thus to translate ethics into contemporary healthcare research. I will discuss the results of my research with regard to the appropriateness of this method and draw conclusions for healthcare research, taking into account the clinical and individual relevance.

2.1.3

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Ethical considerations in psychiatric euthanasia

Psychiatric euthanasia is a highly debated and controversial practice within the realm of medical ethics. It involves the deliberate termination of a patient's life at their request, typically due to severe and untreatable psychiatric conditions causing unbearable suffering. This form of euthanasia raises numerous ethical, legal, and societal concerns.

The aim of this study is to primarily analyze three ethical aspects: competence and its evaluation, diagnosis and incurability, and finally, the concept of suffering.

Competence, the capacity to provide informed consent, stands out as a pivotal factor in euthanasia, alongside safeguarding individuals with diminished autonomy. Numerous scholarly works in the literature contend that mental disorders per se do not necessarily impair competence, and thorough exploration of competence tends to result in psychiatric patients being deemed competent, particularly during non-acute phases. However, it is important to acknowledge that instruments for measuring competence have been tailored to specific decisions and procedures, and assuming the existence of a definitive and objective standard for evaluating competence in euthanasia decisions appears overly presumptuous. Additionally, the interview process entails a subjective element in interpreting responses, which, given the irreversible and profound nature of the decision, may necessitate supplementary verification. Furthermore, conducting such interviews demands specialized training and ongoing practice involving suitably qualified professionals.

The concept of irreversibility in psychiatry cannot be directly transposed from the concept of irreversibility in organic diseases. Prognostic studies reveal errors in over half of cases, highlighting the limitations of current systems for classifying mental disorders. The diagnostic system in psychiatry is just descriptive, not explicative, and a single diagnosis does not necessarily imply a specific etiology or a uniform prognosis, leading to the inclusion of patients with diverse characteristics under the same diagnostic label.

Lastly, there are various approaches to the concept of suffering caused by mental illness. An additional critical consideration pertains to the delineation of psychological distress, which incorporates sensations of despair, lack of agency, and the perception of suffering as unalterable, enduring over an extended duration. These variables engender ambiguous circumstances, affording substantial leeway for subjective interpretation.

Psychiatry holds a twofold responsibility, both clinically and legally, to protect patients from the harm caused by mental illnesses and suicidal inclinations. This stance poses a dilemma, as it raises the prospect of conflicting with the idea of endorsing or facilitating assisted death.

Considering this, we contend that a thorough comprehension of the needs and capacities of individuals with mental disorders is imperative prior to contemplating euthanasia for this population. This necessitates a comprehensive reevaluation of pharmacological therapies and the establishment of robust psychosocial interventions aimed at cultivating supportive communities capable of encouraging and aiding all their constituents.

2.1.4

Jonas Karneboge, University of Siegen, Psychological Aging Research (PAR), Siegen, Germany

Project ESDA: Evaluation of Supported Decision-Making Strategies for Monoclonal Anti-Beta-Amyloid Antibodies

Introduction

Autonomy in decision making for people with dementia (PwD) is of increasing importance, especially in the light of new treatment options such as the disease-modifying antibody lecanemab. These treatment options pose new ethical challenges as they offer potential benefits but also carry increased risks. In this context, supported decision-making (SDM) is essential to enable individuals to make informed and autonomous treatment choices.

Background

Alzheimer's disease, the most common form of dementia, is characterised by amyloid plaques that play a central role in its progression. Lecanemab offers the potential to reduce these plaques and slow the progression of the disease. However, it also carries risks such as amyloid-related imaging abnormalities (ARIA). This duality of benefit and risk highlights the need for informed decision making.

Research objective

The ESDA project extends research on decision support for PwD by investigating both the non-inferiority of an economic capacity assessment in daily clinical practice and the effectiveness of specific SMD tools. The aim is to provide specific SDM tools to support PwD in their decision making regarding lecanemab treatment.

Methodology

The first sub-study includes clinician-assessed capacity assessments of a PwD in the context of disease and treatment disclosure using MacCAT-T (~20min) and BCAT (<10min), and tested for equivalence. The second part will use a randomized controlled multi-arm study approach to evaluate the effectiveness of specific SMD tools, such as priority cards, elaborated plain language or keyword lists.

Results

Preliminary results of the capacity to consent equivalence study are presented.

Significance and expectations

The study addresses a critical gap in current practice and research by providing evidence-based approaches to decision support for a complex and important medical decision. The results will address the emerging risk-benefit profile of dementia treatment and will have direct implications for prescribing practice.

2.1.5

Martin Jungkunz, National Center for Tumor Diseases (NCT) Heidelberg, Section for Translational Medical Ethics, Heidelberg, Germany
Eva Winkler, National Center for Tumor Diseases (NCT) Heidelberg, Section for Translational Medical Ethics, Heidelberg, Germany

Bridging the gap between theory and practice – development and implementation of ethical policies for translational genomic research

In the context of genomic research, difficult ethical questions are frequently raised due to the sensitivity of genomic data, its comprehensive informative value, and the rapid technological progress in which genomic research takes place. If genomic research is carried out in a healthcare-related (translational) context, additional questions arise, as the interface between the areas of research and treatment is often ethically conflictual due to different underlying ethical principles. Ethical guard rails that take into account the ethical theories and principles of both – research ethics and clinical ethics – and translate these into practice are therefore particularly important in the context of translational genomic research. In general, such ethical guard rails can be created through practical policies. To be able to translate ethics into practice, i.e. to bridge the gap between bioethical research and its implementation, these policies should be theoretically sound on the one hand, i.e. they should reflect and build on the body of theoretical ethical and empirical ethical research on the respective topic. However, they should also address specific practical issues and provide their addressees with practicable recommendations for action. In addition, the implementation of the policies should be promoted both by the external framework conditions and by the provision of necessary and helpful materials. Finally, the policy and its implementation should be evaluated. The Heidelberg-based EURAT Group has been addressing various ethical topics arising from the practice of translational genomic research for several years and has already published corresponding policies that serve genomic researchers in Heidelberg and beyond as guard rails for ethical conduct in difficult situations. In our presentation, we will outline the development of the policies published by EURAT with their attempt to do justice to both, theoretical soundness and practical helpfulness. In addition, we provide an insight into how EURAT implements these policies and how this implementation is supported by the publication of materials such as consent forms and patient information on the one hand, and by offering training courses on the other. Furthermore, we will show how the EURAT Group contributes to an environment that enables and promotes action according to their policies.

2.1.6

Yoshinori Mori, Gunma University, Medical Philosophy and Ethics, Maebashi City, Japan

Japanese Public Medical Insurance System in Crisis

Medical care is essential for human beings to have a life with dignity. Therefore, it is an ethical obligation for the welfare state to guarantee the right to medical care to its citizens. In this respect, Japanese public medical insurance system is very unique and remarkable.The most distinctive feature of Japanese public medical insurance system is “universal coverage,” that is, an insurance in which all the citizens are covered as subscribers. Universal coverage was achieved in 1961 and is still maintained today. More specifically, Japanese public medical insurance system can be characterized by (1) high degree of equality, (2) open access, and (3) strong control through public pricing. For example, in Japan, subscribers are not required to pay for medical expenses above a certain level, and the excess is paid by the public insurance. In addition, with an insurance card, Japanese citizens can receive treatment in almost all hospitals. Finally, every price for all medical treatments is determined by the government (Ministry of Health, Labour and Welfare) and is kept uniform throughout the country. The long life expectancy (male:81, female:87=2022) and low infant mortality rate (1.7/1000, world average:31/1000=2021) of the Japanese would not have been possible without the existence of such a wonderful insurance system. On the other hand, the national medical expenditure in Japan was about 135 billion dollars in 1990, but exceeded 200 billion dollars in 2000, 270 billion dollars in 2013, and reached 303 billion dollars in 2021. In a word, Japanese medical expenditure has increased continuously over the past several decades. Furthermore, the declining of birthrate and the aging of population were simultaneously and rapidly accelerated. As a result, productive population who can financially support medical insurance has decreased, and Japanese public medical insurance system stands on the verge of extinction. To address this situation, the Japanese government seems to have two options: (1) reduce medical expenditures or (2) increase the burden of insurance premiums. Adopting (1) would mean that the Japanese government would sacrifice the quality of medical care and abandon its responsibility to guarantee the right of its citizens to adequate medical care. On the other hand, given the current situation where millions of people are already unable to pay their insurance premiums, adopting (2) would lead to the collapse of universal coverage. Consequently, whichever option is chosen, the government would give up its ethical obligations mentioned above.Is there, then, the third way to overcome this crisis without undermining the sustainability of Japanese public medical insurance system? In this presentation, I would like to explore the possibilities of “the third way.”

2.1.7

Ivica Kelam, Faculty of dental health and medicine - Josip Juraj Strossmayer University of Osijek, Department Of Interdisciplinary Areas, Tenja, Croatia

Overview of Ethical Education Among Healthcare Workers in Croatia

In our presentation, we will provide a comprehensive overview of the state of ethical education of healthcare workers in Croatia. Through the synthesis of research findings and institutional data, the presentation delves into the current landscape of ethical education initiatives in the Croatian healthcare system, where we will analyse the level of ethical education at all levels from the ethical training of medical doctors to nurses.. It emphasises the importance of ethics education in fostering professionalism, improving patient outcomes, and maintaining the integrity of the health profession. In the presentation, we will emphasise the challenges faced by ethical education of healthcare workers in Croatia, such as curriculum integration, training of teaching staff and resource constraints, while exploring innovative approaches and best practices to improve ethical education among healthcare workers. Additionally, it emphasises the importance of interdisciplinary cooperation and engagement of stakeholders in fostering a culture of ethical awareness and responsibility. Providing insight into the strengths, weaknesses and opportunities for growth in ethics education, this presentation aims to stimulate dialogue, inspire action and promote continuous improvement in the ethical preparedness of healthcare professionals in Croatia.

Keywords: ethical education, health professionals, Croatia, medical ethics, professional development.

3.1.1

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Ethical Navigation in Rare Disease Care: Understanding and Acting on Parents' Insights to Improve Quality of Life

Background
Globally the number of children and adolescents living with a rare disease is increasing due to improved periconceptional care, advances in diagnostics and treatments. Therefore, it is essential to better understand their experiences and viewpoints on quality of life. Most quality-of-life studies, however, are quantitative and focus primarily on disease-related variables. However, as the concept of "quality of life" has fundamental ethical requirements, this study on "quality of life" is an example of how an ethical concept can be meaningfully translated into healthcare practice.

Question/Aim
This qualitative study aimed to explore child and family-focused experiences of quality of life. Given the possible cognitive impairment and motor dysfunction in many children with rare diseases, questions regarding quality of life were addressed to parents. The ethical concept of quality of life was thus transferred to practical decision making in medicine.

Methods
Participating parents were recruited via the knowledge network for children with rare diseases (KMSK). Qualitative data from open-ended survey question on parents' perceptions of children's quality of life were analyzed using content analysis. Data collection took place in 2023.

Results
The study included 108 primary caregivers of children with rare diseases. Despite various diagnoses, parental perceptions of their child"s quality of life shared many commonalities. Five categories of parental perceptions of children"s quality of life were identified: (1) pain-free living and joy; (2) partaking in everyday life; (3) the quest for integration: desire for normality and appreciation of difference; (4) obtaining developmental milestones and (5) having access to individualized child- and family-centered care.

Conclusions
In addition to positive health outcomes, also social integration, respect for non-traditional developmental trajectories and holistic healthcare services were reported as an important part of "quality of life". To facilitate social integration, healthcare professionals should be aware of parents' concern about stigmatization. Parents also underlined the importance of them, and their children being listened to by the medical staff. The feeling of being unheard or not being taken seriously can cause distress. Epistemic justice should thus be part of individualized child- and family-centered care. This would be an example of how translational ethics can be put into action.

3.1.2

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

On June 25, 2021, Organic Law 3/2021 regulating Euthanasia entered into force in Spain. This regulation places Spain as the fourth European country to decriminalize euthanasia and assisted suicide, and the first one to do so with a prior control system to its implementation by a Commission for the Guarantee and Evaluation.

The legislator"s will be to give guarantees to the citizen that the established requirements would always be met and that the authorization for euthanasia would have a prior and not subsequent supervision, as it happens in the Netherlands, Belgium or Luxembourg.

The requirements to access euthanasia or assisted suicide are: to be a Spanish citizen, at least 18 years old, to request it with full capacity for 2 times with an interval of 15 days or in a document of advance directives, and to be in a situation of serious advanced illness with great physical or mental suffering or in a situation of serious suffering, chronic and disabling that entails severe limitations of daily life and without the possibility of improvement.

The control of the Commission has been established with territorial scope so that each autonomous government has its own commission that must review and authorize or deny case by case, after a report from 2 doctors. This procedure slows down the process but gives it greater legal certainty. From the Commission of Catalonia, of which I am part as a senior jurist, we have already a very rich experience, having reviewed more than 350 applications. But, after two years of application, the situation is very diverse in the different territories of Spain, generating great inequality for Spanish citizens. Ideological and political aspects influence the activity of professionals and the Commissions, generating blocking and paralysis of files, to the detriment of patients who do not see their requests met.

This communication presents the results of the 2022 Annual Report of the Ministry of Health as well as the detail of the activity of the Commission of Guarantees of Catalonia, which presents higher figures. Also, in these firsts" years, difficulties have appeared in interpreting the law according to the cases: mental health diseases, chronicity and old age suffering, value of advanced directives, etc., that we are trying to solve case by case.

3.1.3

Anna Hirsch, LMU Munich, Institute of Ethics, History and Theory of Medicine, Munich, Germany
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Practicing ethical discourse as a means of translating ethics into healthcare practice: Experiences from a participatory teaching project on biomedical enhancement

Teaching clinical ethics to medical students can be seen as a means of translating ethics into healthcare practice – but only if it meets certain requirements. It should relate to the (future) professional life of the students and be able to increase the chances that ethical requirements are met in practice. This can be achieved by addressing ethical challenges that medical students will face during their work as physicians and give them opportunities to learn how to adequately deal with them. The competence-oriented teaching of medical ethics can be an approach that meets these requirements. Instead of merely imparting knowledge about ethics, students are provided with opportunities to acquire ethical competences, e.g., the competence to identify and discuss ethical problems, conflicts, and challenges in patientcare.

Case discussions are a well-known method within competence-oriented teaching. However, there are other didactic methods that should receive attention. Consensus-oriented ethical discourse has the potential to promote the development of ethical competences. It makes sense to involve medical students in their design and organization in order to align them as closely as possible with their everyday world.

In my talk, I will present a participatory teaching project that can be seen as a good practice example of how teaching clinical ethics to medical students can be designed as a means of translating ethics into healthcare practice. In our teaching project, we involved medical students in three different roles: as teachers, as researchers, and as both seminar and group delphi participants. In all three roles, we enabled them to acquire different competences. Two students in the fourth year were directly involved in the organisation of the learning environment: They identified topics and methods for the seminar, prepared and conducted the seminar supported by experienced lecturers, organised a group delphi discussion as part of the seminar, and wrote a research report on its conduct. Other students took part in the seminar as well as in the group delphi discussion and wrote an essay on two aspects of the group delphi"s discussion. The primary aim of the project was to promote the ability of medical students to critically analyse and discuss ethical issues in medical practice, put arguments under scrutiny, and develop and revise attitudes. The topic centred on ethical issues in connection with biomedical enhancement. Two overarching questions in particular took centre stage: What are legitimate goals of medicine in patient care? Which methods of biomedical enhancement should fall within the scope of medical practice, and which should not?

I will present the didactic conception of our project, its implementation, and the challenges we encountered. In addition, I will outline the results of our project, discuss the competences we wanted to help students acquire, and point out the advantages of teaching medical ethics as we did it. By presenting our teaching project, we hope to inspire the realisation and further development of similar projects in teaching medical ethics to medical students.

3.1.4

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Contributing to a more Coherent and Comprehensive Understanding of the Research Ethics of Deception: an Interview Study with Researchers

Question
Also in health research, the deception of research participants is a methodology used to improve study validity and reliability. As deception is an ethically sensitive practice, research ethics guidance on this kind of research methods has been around for decades. However, there are problems with both the formulation of recommendations (e.g., incompleteness and inconsistency) as well as their implementation in practice (e.g., unwarranted variability). Therefore, our study aimed to contribute to a more coherent and complete understanding of the research ethics of deception and the ethical safeguards implemented in deceptive studies (e.g., debriefing), in a way that can accommodate the realities practitioners face when making ethical decisions about deception.

Methods
To do so, we have interviewed 24 researchers with recent and extensive experience using deception, coming from a variety of scientific disciplines and using a broad range of deceptive study designs. Following semi-structured interviews, several rounds of inductive thematic analysis were performed. Subsequently, the inductively generated themes were abductively compared to insights from the academic literature to assess convergence and divergence between our results and the literature.

Results
On the one hand, the interviews clarified how the different components of deceptive methods can affect the justifiability of deceiving participants. For instance, whether a researcher induces a false belief in the participant by lying or by withholding information constituted an ethically relevant difference according to interviewees. On the other hand, interviewees" accounts allowed for a more coherent picture of the different ethical safeguards that can prevent or mitigate the harms and wrongs due to the deception, as well as of how the safeguards in deceptive studies relate to the notion of truthfulness. For instance, while all deceptive research also includes some truthful information, how this was communicated to participants varied significantly between interviewees. This could in turn affect the impact of resulting true beliefs on participants (e.g., mitigating harmful effects of the deception by debriefing participants) and on the study"s methodological value (e.g., pre-deception truthfulness can decrease the methodological benefit of deception).

Conclusions
Our study has contributed to a better understanding of the use of deception in research and the safeguards implemented in such studies. In conclusion, several concepts require further exploration, such as the safeguarding role of implicit truthful communication in covert research. Further normative analysis of the presented findings should accompany our descriptive understanding of the ethics of deception in order to contribute to improved research ethics guidance.

3.1.5

Lea Wilken, Hamburg University of Applied Sciences, Health Sciences, Hamburg, Germany
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Ethical implications of integrating new technologies in clinical routine: trust and autonomy in the realm of personalised medicine.

Background

Since a while, the evidence of salty sweat has been used to diagnose cystic fibrosis (CF). Within the realm of personalised medicine, our international research project has developed a method for in vivo assessment based on new technology that enables more precise diagnoses as well as an optimised treatment for CF. The implementation of this new method involves new ethical implications. As the ethical sub-project of this joint project, we are investigating the ethical implications of integrating this new technology into everyday clinical practice. Our aim is to identify ethical challenges, uncertainties and problems in dealing with this new diagnostic tool.

Question

In this regard, the primary research questions of our ethical research project are: (1) What ethical challenges, uncertainties and problems arise when dealing with new technological artefacts, especially diagnostic tools, in the everyday medical practice of patients and physicians? (2) What attitudes do patients, physicians and medical staff have towards the importance of autonomy and trust in relation to the clinical use of diagnostic tools?

Methods

We are focusing on an empirical-ethical, practice-oriented approach. Over the next months, we will conduct semi-structured interviews with patients, physicians and medical staff, who are involved in the new diagnostic procedure and its testing process. Thereby we cooperate with our clinic partner from the ERAPerMed consortium Stracyfic in Germany, France, Belgium and Italy. Furthermore, the patient organisation, Mukoviszidose e.V., is our cooperation partner, who will support us in the preparation of the interview study as well as in its conduction. Our research focuses on attitudes towards the relevance of autonomy and trust in relation to the clinical use of the new diagnostic tool. The empirical data will be analysed by a qualitative content analysis. This method enables us to gain important insights and incorporate them directly into the development and implementation of new technological artefacts in clinical practice. In this way, we want to ensure that ethically relevant aspects are not neglected in the application of new technologies. Our work thus represents a translating bridge that connects theoretical ethics with practical application in healthcare.

Results

Preliminary results from our ongoing empirical-ethical study will be presented, providing insights into the daily medical-diagnostic world of patients, physicians and the medical staff in dealing with these new technological artefacts in clinical routines. In this context, we will focus mainly on the relevance of the ethical aspects of trust and autonomy in this procedure. Furthermore, due to the transnational nature of our research project, we will also identify and analyse transnational differences and similarities that arise in the clinical use of the new diagnostic tool.

Conclusion

The preliminary results of our ethical-empirical study help to identify ethical problems to develop a standard operating procedure in order to integrate the new diagnostic technology at other clinics in the best possible way by translating ethically relevant aspects into healthcare practice.

3.1.6

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Telehealth in palliative care settings: A systematic review of argument-based ethics literature

Background

Telehealth has seen a significant rise in popularity and widespread adoption in various healthcare settings. One example is the incorporation of telehealth into palliative care. Instances of the application of telehealth in palliative care include remote monitoring of patients at home, virtual consultations with palliative care specialists via videoconferencing platforms, and the integration of mobile palliative health applications to improve patient care and support. Despite the potential benefits that telehealth brings to palliative care, it also introduces a multitude of ethical considerations that warrant careful examination. While the literature extensively discusses ethical issues within both telehealth and palliative care separately, there remains a gap in understanding the unique ethical concerns arising from the intersection of these two domains. Therefore, it is imperative to explore and address the specific ethical challenges that accompany the implementation of telehealth in palliative care settings.

Objective

This study aims to describe and analyze the main ethical concepts used in the debate on the use of telehealth in palliative settings and the arguments based on these concepts.

Methods

We are conducting a systematic review of the argument-based ethics literature. Articles will be selected based on the following predefined inclusion/exclusion criteria: (1) published articles containing fully elaborated ethical arguments; (2) focusing on telecare; (3) focusing on palliative care settings. We will conduct searches in the following databases: Medline, Embase, Web of Science, Scopus, CINAHL, APA PsycArticles, ProQuest Central, Philpapers, Philosopher"s Index, Atla Religion Database, IEEE Xplore, and ACM Digital Library.

Results

As our research is ongoing, we cannot provide specific findings at the stage of abstract submission. However, we will have results ready for presentation at the conference. We anticipate that our study will enhance understanding of the ethical aspects of telepalliative care, guiding future research and practice in this field.

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3.1.7

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Assessing the ethical implications of using telemedicine to support patients with advanced Amyotrophic Lateral Sclerosis (ALS)

The advanced phase of Amyotrophic Lateral Sclerosis (ALS) is a critical period with a high risk of complex, inadequately controlled symptoms, hospitalizations that are sometimes difficult to cope with, and exhaustion of caregivers. In such a context, teleconsultation (TLC) can improve the quality of care in the advanced stages up to death, by limiting hospitalization, preventing complications and caregiver burnout, and providing access to palliative care. Although few in number, studies therefore exist in the literature and offer initial forms of medical evaluation of TLC (Van De Rijn et al. 2018) (Geronimo et al. 2017) (Selkirk et al. 2017) (Nijeweme-d'Hollosy et al. 2006). However, intervention in the home by ALS Center hospital professionals via telemedicine raises numerous ethical issues that have been little addressed in the literature. This presentation will explore these ethical issues, focusing on how telemedicine is transforming the healthcare environment. Indeed, "several works (notably Cartwright, 2000; Nicolini, 2007, Dyb and Halford, 2009; Peterson, 2011; Oudshoorn, 2012) are committed to showing that the use of telemedicine does not lead to an abolition of borders and spaces, contrary to a common sense vision often implicitly carried by public policies" (Mathieu-Fritz and Gaglio 2018: 42). On the contrary, telemedicine acts require a certain rearrangement of spaces in order to take place, and even, in the case of teleconsultation of patients with advanced ALS, a hybridization of the care spaces of the home with the more codified space of the hospital.

4.1.1

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Translating Ethics into Action: Ensuring Advocacy, Autonomy, and Access in Disability Care

Background
The treatment, care, and support of people with disabilities and impairments in outpatient and inpatient care faces different challenges. These challenges arise, among other things, from the fact that people with cognitive impairments, for instance, are not able to express their wishes clearly, or people with physical limitations encounter many barriers in healthcare. However, the fundamental principle of human dignity demands that advocacy, autonomy, and access in disability care are considered and that an "inclusive medicine" is mandatory. This "inclusive medicine" is an example of how translational ethics can be put into healthcare practice.

Question / Aim
The aim of this project was to examine and define the requirements for the development of practical tools and concepts for outpatient and inpatient care, in order to provide medical treatment, care and support for people with a disability or impairment to ensure their advocacy, autonomy, and access in healthcare.

Methods
The project used a mixed-methods approach (semi-structured interviews, focus group discussions, online surveys) to examine the perspectives of people with disabilities and impairments, their proxies and professional guardians, health care professionals in hospitals, medical and therapeutic practices, and employees in care institutions. In total, 26 in-depth interviews with people with disabilities and their proxies, five focus group discussions with employees in hospitals, care institutions, physicians, and professional guardians as well as three different online surveys with 928 participants (119 employees from two care institutions, 129 resident doctors from Zurich and Central Switzerland, and 680 employees from two cantonal hospitals) were carried out. The results from the various work packages were incorporated into the development of practical instruments and concepts after an ethical assessment and scientific classification – in addition to considering the current state of knowledge from the specialist literature.

Results
As a result of the project, proposals for a total of 14 monitoring, training and support instruments and concepts were developed. The practical tools and concepts that were proposed are: Advanced training and further education of health professionals, a contact person for the concerns of hospital patients with disabilities, round-table discussions and ethical case reviews, a web-based information platform and a treatment agreement. The instruments are summarized in a report and first publications which can be found on the website: www.dialog-ethik.ch/inklusive-medizin.

Conclusions
The 14 monitoring, training and support instruments as well as concepts that were developed in the project can not only improve treatment, care, and support of people with disabilities, but are also highly likely to relieve the strain on relatives, guardians, and health professionals in general. The overarching objective of implementing these tools and concepts is to strengthen the autonomy of people with disabilities, to help develop mutual appreciation and thereby to reduce injustice. This in turn will allow people with disabilities, their relatives, and guardians to trust that they receive adequate treatment, care, and support.

4.1.2

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What information is important to patients with a family history of breast and ovarian cancer when giving informed consent to genetic testing?

Question

Written informed consent forms are generally extensive and complex. It is an ethical imperative that patients must be provided with comprehensive information to exercise their rights. However, this leads to patients being overwhelmed by the detail and complexity of the information, and, in the worst case, to "box-ticking" rather than genuine self-determination in medical decision-making [1; 2]. In addition to providing information, trust in physicians has been suggested to play an important role in decision-making [3]. Moreover, even if patients in fact understood all information provided, they may not consider every aspect important. The aim of our research was to better understand the patient"s perspective on informed consent forms in the context of genetic testing.

Methods

We conducted a cross-sectional online study as part of the G-BA funded project dVP_FAM (01NVF20002) with N = 224 women with a family history of breast and ovarian cancer. Using a self-report questionnaire, we asked participants to rate the importance of 14 items typically covered in informed consent forms ("consent aspects", e. g. length of storage of genetic data, usage for research purposes and various data protection aspects in relation to genetic testing). Each aspect was compared with other aspects using multiple contrast tests for repeated measures [4]. Participants were also asked for their hypothetical agreement with each aspect. To assess trust in physicians, we adapted one item from the Cologne Patient Questionnaire [5]. Additionally, the patients" wish to participate in medical decision-making was assessed with one item based on the Control Preference Scale [6].

Results

While the majority of consent aspects were consistently rated as highly important in absolute terms, we observed relative differences. Overall, participants largely agreed with the consent aspects. The majority stated to prefer making medical decisions together with their physician. The spearman correlation between trust in physicians and the importance of "writing down genetic information in physicians' letters" was statistically significant at the 5% level ($n = 190$, $\rho = 0.245$, $p = .016$).

Conclusions

Patients consider some consent aspects more important than others, e.g. "being contacted in case of reevaluation of the test result", "being notified about additional clinical findings" and "using the test result for genetic counseling of relatives". These aspects seem to reflect a direct benefit for the individual and their family. It seems likely that medical decisions are not merely based on information but on trust in the physician and the institution she is affiliated with [3]. Our results provide a basis to create an alternative consent form which reflects patient"s preferences and is in line with the European legal requirements. Such a consent form may support patients in making self-determined decisions by highlighting the aspects they consider important [1; 7]. [1] O'Neill (2003). Some limits of informed consent. *Journal of Medical Ethics, 29*(1), 4–7.[2] Brand et al.(2019). Annals graphic medicine-patient-informed consent. *Annals of Internal Medicine*, *170*(8), W90-W106.[3] Kongsholm & Kappel (2017). Is consent based on trust morally inferior to consent based on information?. *Bioethics, 31*(6), 432–442.[4] Rubarth, Pauly, & Konietschke (2022). Ranking procedures for repeated measures designs with missing data: Estimation, testing and asymptotic theory. *Statistical Methods in Medical Research, 31*(1), 105–118.[5] Scheibler et al. (2011). Entwicklung und Validierung der Skala „Vertrauen in den Arzt" im Kölner Patientenfragebogen (KPF). *Klinische Diagnostik Und Evaluation, 4*, 63–77.[6] Degner, Sloan, & Venkatesh (1997). The control preferences scale. *Canadian Journal of Nursing Research Archive*, 21–44.[7] Ludewigs et al. (2022). Ethics of the fiduciary relationship between patient and physician: the case of informed consent. *Journal of Medical Ethics*.

4.1.3

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The creation of an Ethical Space within an Italian Territorial Social Health Agency to encourage community welfare.

Background/Question

The Espace Éthique d"Assistance Publique, created in the Hôpitaux de Paris in 1995 by Emmanuel Hirsch, with the support of Alain Cordier and Didier Sicard, represents a significant landmark in the field of health and care ethics. This space was created to address complex ethical issues related to health care practice and patient care. It was created as a space for ethical reflection that takes part in raising awareness and training of health care professionals; it also constitutes a documentary resource center that collects the material needed to develop a culture of care and the defense of hospital values; facilitates exchanges between professionals and representatives of academia and associations involved in the field of life and health sciences; encourages meetings between representatives of patients, families, and members of civil society. In the years that followed, numerous other Ethical Spaces sprang up, distributed first in the French territory, and later, in the wider european territory. *Ethical* Spaces have also begun to be created in the Italian context thanks to the movement of the cultural association "Spazio Etico" operating in Italy in 2013 by Professors Bernardeschi and Favero. The work done, as well as the Espace Ethique, is placed upstream of practices and becomes a way to develop the culture of care, defend professional values and give propulsive thrust to good practices and change (De Simone, 2023).
The CNB (2021) published a document dealing with the role of Ethical Space, recalling the relationship between vulnerability, community welfare and "Places of care", considered, not only as an institutional system of care, but also as moments of attention and listening. It stresses the need to foster the development of community welfare, in which individuals, famiglie and associations seek to build new forms of encounter and care. According to the RRP, "Community Houses" will be places to enhance social welfare, dedicated to listening to the needs of the weakest and most fragile individuals. Starting from the reflection on vulnerability, in its deep connection with the ethics of care (known as "taking care"), the CNB (2021) defines the multiple applicative potentialities of a model called Ethical Space.

Material and Methods

Thus, a project for the creation of an Ethics Space within an Italian Territorial Social Health Agency "ASST dei Sette Laghi" was then presented and approved. The first phase of the project was characterized by the formative design of a pathway aimed at promoting and sensitizing health workers on the topic of humanization of care and moral and values literacy, and on issues related to clinical practice. Next, an institutional channel of communication between Ethics Space facilitators and employees was identified. Finally, the physical spaces that will house the Ethics Space were identified and meetings were scheduled for the year 2024.

Results and Discussion

The first no. 12 professionals who, through interest and motivation, indicated that they would like to make a valuable contribution to the project, participated in the training. After the presentation of the project, in all its phases, the theoretical foundations useful to assume the role of facilitatore within the Ethics Space were shared. Afterwards, a practical exercise on the theme of values was proposed. The Go Wish Game (Perin et al., 2022), which aims to stimulate reflection and sharing on topics such as Informed Consent, Advance Treatment Provision, and shared care planning, provided professionals with the normative and ethical tools useful for talking about personal values and planning care choices during the illness journey and at the end of life.

Conclusions

In addition to fostering the relationship between professionals, it also offered useful strategies for dealing with ethical and values problems and/or dilemmas to support colleagues who, due to different needs, will turn to the Ethics Space.

4.1.4

Emma Capulli, University of Bologna, Bologna, Italy
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Research involving informal caregivers of patients with dementia: challenges related to information sharing

As life expectancy increases and the population ages, a growing number of people are affected by dementia. It is estimated that the global population affected by dementia will reach 75.6 million by 2030 and 135.5 million by 2050. In parallel, the number of informal caregivers who take care of people with dementia increases. These caregivers may be exposed to significant burden and stress and therefore it is important to investigate and monitor their health status and wellbeing, also to develop preventive interventions. Moreover, there is some evidence that the behavioural and psychological symptoms of dementia have a reciprocal relationship with caregivers" own physical and mental health. Within a non-therapeutic study involving informal caregivers of patients with dementia, we faced the following question: "Is it ethical to collect data concerning the person with dementia from his/her caregiver?".

To address this question, the following issues should be considered: how the privacy of people with dementia should be understood, whether involving the patient with dementia is necessary to obtain information from the caregiver, and how to deal with different levels of patient competence in this context. Dementia is characterized by a progressive decline in autonomy. Recently, some scholars have discussed concepts such as "assisted autonomy" and "sharing agency", rejecting a paradigm that views dementia solely as loss and instead emphasizing the new shared dimension that agency can assume. Adopting a similar approach towards privacy of people with dementia, our focus will not be on preserving their maximum independence in handling information, but rather on improving the sharing and interdependence involved in managing it. In this regard, we should also consider how cultural differences and backgrounds may affect how privacy is conceived. Our reflection continues by arguing that the progressive decline of autonomy and agency does not negate the right to privacy, which remains crucial for respecting the dignity of people with dementia. Furthermore, although compromising privacy may be deemed acceptable in certain circumstances to safeguard public interest or patient safety or well-being, in the context of non-therapeutic research involving their caregivers, there are no direct benefits for the patients. Given these considerations, it would be considered desirable to involve people with dementia when information concerning them is shared. This requires considering different approaches to involve patients with dementia according to their level of competence. Our goal is to foster a discussion aimed at finding a balance between safeguarding the privacy of patients with dementia and the need to carry on rigorous research involving informal caregivers, whose results have the potential to benefit both caregivers and patients in the future.

4.1.5

Kenji Hattori, Gunma University, Department of Medical Philosophy and Ethics, Maebashi, Gunma, Japan

A New Approach to Improve Clinical Ethical Competence

Clinical ethics can be divided into two types: speculative or meta-clinical ethics, and behavioral or on-site clinical ethics. While both are complementary, the former is relevant to speculative ethics as a discipline that has attracted so much attention and every effort. The latter, on the other hand, is the subject of this paper.

Healthcare professionals and students must respond, at least tentatively on the spot, to ethically problematic situations in clinical settings on their own, without or before receiving any help from MCD or consultation. Thus, by modifying Augusto Boal's *Forum Theater*, we have developed an innovative pedagogical method, called *Clinical Theater*, for trainees to develop flexible, improvisational competence and to reflect on how they responded, including not only verbal expression but bodily expressions, when facing ethically challenging situations. In *Clinical Theater*, several professional actors act out a series of dramatic scenes. The trainer stops the play in the middle and encourages the trainees to point out problems and respond to patients and their family members by taking on the role of a medical professional in the play. The actors respond immediately to what the students express. After several rounds of such improvisational communication, feedback and comments are exchanged among all the trainees, the actors, and the trainer.

While *Clinical Theater* has proven so effective in our three years of training experience, the method does have some weaknesses. The first is the difficulty of assembling professional actors for each *Clinical Theater* class, and the second is its financial burden. To address these challenges, we have embarked on a new project to produce completely unique educational video materials. In this paper, we show some parts of the actual materials, and explicate their design, advantages and disadvantages.

4.1.6

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Philosophical and theoretical aspects of translational bioethics

There are at least three possible approaches to the topic of translational bioethics, which are attempted in this paper.
The first concerns ethical and *philosophical theories of contemporary thought* that foster an approach such as translational bioethics: I refer in particular to various currents of contemporary philosophical hermeneutics (in particular with the figure of Paul Ricoeur) as well as so-called dialogical thought (Franz Rosenzweig, Emmanuel Lévinas, Martin Buber). Although these currents do not exhaust the dimension addressed, they are significant examples of a dynamic reason in action (*denken* as verb) and not only a fixed one (*Denken* as noun). Hermeneutics in particular establishes a circularity between the theoretical and applicative dimensions, just as dialogical thinking structurally establishes a link between the foundational and pragmatic dimensions. Both are founded on the centrality of the word, but also on an openness of truth that is not exhausted in a definitive meaning. This is particularly significant for a bioethics 'on the way'.
The second approach is internal to bioethics, seeking to *avoid the opposites* of deductivist principialism and empirical bioethics, which seems to run the risk of 'bioethical positivism'. Translational bioethics, on the one hand, recovers the empirical research dimension proper to empirical bioethics, but does not renounce an epistemological outlook that treasures even different principles, values and paradigms within the bioethical dimension, without falling into the implications of pure principialism. From this point of view, transaltional bioethics is necessarily dialogical bioethics, both on the internal epistemological level, in the relationship between different ethical principles, values and theories, and on the educational and civil level, on the relationship between different cultural, anthropological, political and religious approaches.
The third element relates to the link between *research and* its *application.* Bioethics has suffered from an excessive philosophical bias as well as a parallel call to the empirical dimension, often taken over by scientific knowledge without an adequate internal translation. Translational bioethics offers a synthetic dimension between humanistic and scientific knowledge, as in the premises of the classical bioethical dimension. From this synthetic perspective, a clearer epistemological foundation can also emerge for structuring the practical places of bioethics, from classic ethics committees to the development of ethical expertise in many areas including artificial intelligence and future challenges. In Italian context, the places of bioethics have suffered from this distance, with committees for clinical practice more philosophical but not integrated into institutions, or research committees rooted in institutions but now with only a procedural and not ethical purpose.

PRESENTATIONS

1.2.1

Mark Sheehan, University of Oxford, Ethox Centre, Oxford, United Kingdom

Mistranslations: The Uses and Abuses of Deliberative Democratic Methods

Deliberative democratic methods are all the rage in bioethics and elsewhere, both as tools for decision-making and, somewhat surprisingly, for research. In this paper, I consider a range of different deliberative methods as they are often used in bioethics research and in ethics-related policy making. I argue that we must be clearer about the role of democratic methods, whether they are deliberative or not, as well as the supposed advantages of the deliberative form. From these considerations, we are well placed to distinguish the uses from the abuses: broadly that these methods have limited use in bioethics research but for certain kinds of localised decision-making, they can be well used for legitimate decision-making.

1.2.2

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Jan Schildmann, Martin Luther University Halle-Wittenberg, Institute for History and Ethics of Medicine, Halle (Saale), Germany
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"From book to bedside?" or: Alternatives to drawing an ethical analogy to translational medicine?

We will argue, that the "translational" in translational bioethics deserves some critical reflection. An analogy to translational medicine is too weak to provide helpful guidance as to what the goals of translating ethics are or how translation should be carried out, whereas other conceptions of translation are missing.
"Translational" is a widespread expression to denote a type or goal of bioethical research. It rarely refers to ethical questions of translation in the linguistic sense or to ethics *of* translational medicine. An analysis of the literature demonstrates frequent explicit references to translational medicine instead. In some cases, an implicit reference to translational medicine can be ascribed.
In translational medicine, pre-agreed research phases help developing knowledge about effects (and side-effects) in a time- and cost-effective way, moving from research objects that are easier to access to research objects that are closer to the real-life situation of new interventions. The research phases are useful to balance delaying factors (especially risks) and accelerating factors (urgency, public health needs, financial interests) of product development. The analogies to ethical research are scarce. From this perspective, characterizing ethical research as "translational" appears as an attempt to make use of the acceptance of translational medicine in an unjustified way.
Motivating for looking for "translation" in biomedical ethics too seems to be a wish for more ethical work that targets real-world issues and for conducting research on them in a way that increases the chances that it has well justified real-world impact. This may require applying empirical methods to topics of initial problem analysis and estimating consequences of changes in real-life that ethicists propose. Though this motivation is reasonable, it is likely that – in this sense – more practical ethical work can take several forms: Different kinds of results (Recommendations? Interventions? Theories?), different methods and relations of ethical theory and results. So far, only a few models of bioethical "translation" have been proposed that might provide a sense of methodological unity among more applied or practical ethical work. However, these models also have their specific presuppositions and limit the scope of translational bioethics to, for example, questions of changing practice in way that was already identified as good from a normative perspective. While there are at least some attempts to be more explicit about the role of empirical studies for normative questions, they can not be used as plausible models of strictly deriving ethical recommendations from empirical research. The extent to which these attempts of connecting empirical and normative research are suitable for "translational" purposes has not been clarified sufficiently.
This lack of general methodological guidance concerning "translation" maybe is not a flaw but a typical feature of a discipline that reflects on the diverse moral aspects of health care practices. Criteria for practical results of such reflections might be highly context-dependent. Assuming phases or structural models by drawing on analogies to translational medicine might even obscure the sometimes necessarily fragmented, tentative and interdisciplinary nature of applied ethical research.

1.2.3

Jusaku Minari, Kyoto University, Kyoto, Japan

The Need for Reverse-Translational Bioethics in Health Research and Healthcare Practice

The nature of translational ethics has recently garnered attention, including in regard to its conceptual positioning, implications, significance, specific methods and evaluation axes. The first question that must be addressed in this development is how to define and organise translational ethics. In this regard, a few distinct perspectives can be identified. Does the term *translational ethics* refer to something like applied ethics, to something similar to bioethics in an interdisciplinary sense or to a series of processes by which theory can be applied to practice? Translational research in medical contexts intends to translate and apply scientific findings and knowledge to medical practice as a form of social benefit, so the most important question may be what needs to be translated and for which purpose.

From a literal perspective, translational ethics can indicate the application of ethics as an academic discipline to health research and healthcare practice. When translational ethics is discussed from this perspective, the subject matter is likely to be how the norms, theories and knowledge shaped and developed in ethics scholarship can be applied to health research and healthcare practice. In this case, a key matter of debate is how specifically to apply and manage these diverse principles and theories in an actual society. In such a translation, however, the concepts and meanings that have been established in theoretical ethics may be distorted in the process of translation. In this vein, it is also possible to ask whether the application of ethics alone will contribute to addressing and optimally resolving major issues regarding health research and medical care.

The view that ethics is one of the relevant disciplines may play a key role in addressing the challenges in health research and healthcare practice. From the perspective of jurisprudence, for example, this perspective embraces examining the significance and interpretation of existing regulations as well as the ethical and legal frameworks that will be needed in the future. From the perspective of medical sociology, the perspective includes considering the nature of informed consent and ethical review in a practical sense. From the perspective of social psychology, it could demand exploring and understanding the perceptions and behaviours of patients and research participants. Accordingly, these views may reflect the concept of bioethics as an interdisciplinary framework.

This presentation will emphasise the necessity and significance of reverse-translational bioethics while touching on the various perspectives described above. In the context of advanced scientific research, this perspective can be found in the U.S. in the framework of ethical, legal and social implications (ELSI) and in Europe in the perspectives of ethical, legal and social aspects (ELSA) and responsible research innovation (RRI). I will discuss the meaning and necessity of reverse-translational bioethics using specific examples in genome research, stem cell research, genome editing research, infectious disease research and artificial intelligence. Reverse-translational bioethics, in this presentation, refers to addressing from interdisciplinary viewpoints the challenges of bioethics arising from actual health research and healthcare practice.

1.2.4.

Marcel Mertz, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany
Hannes Kahrass, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany

"Full" health technology assessment (HTA) reports as a device for "translating" ethics into healthcare practice – observations on the suitability, implementation and reach of ethics in HTA reports

Question
So-called "full" HTA is a multidisciplinary process in which a health technology (e.g., diagnostic devices, therapeutic interventions, drugs) is evaluated from different perspectives. HTA is usually commissioned or conducted by a specific agency/institution of a country (HTA agency). The primary focus are benefits and harms and health economics of the technology. Full HTA reports, however, include also organizational, social, legal and ethical aspects of a technology. The aim of an HTA is to provide practical information and often recommendations as to whether a technology should be, for example, reimbursed by health insurance, or whether (or how) the technology should be implemented in hospitals. Since ethical considerations can also find their way into practice in this way, one may ask: Is full HTA a) suitable for a "translation" of ethical information or recommendations in view of b) the way ethics is implemented in HTA and how c) full HTA reports are received overall?

Methods
The investigation primarily relies on critical-conceptual analysis against the background of existing knowledge about HTA (objectives, methods, reporting, etc.) on the one hand, and the debate and concepts of "translational ethics" on the other. However, there is also an empirical basis in part: Following an in-depth search and query of international HTA agencies, 39 full HTA reports from six countries (Canada, Switzerland, Germany, Austria, Sweden, and Norway) were, inter alia, qualitatively analyzed in regard to the reporting, processing and methods used in the ethics domain.

Results
In this empirical part, heterogeneity was evident within the agencies themselves, but especially in the international comparison. The structure of the reports and interaction of the domains differed. The ethics domains were also treated differently, e.g. in terms of the theoretical background or methods. However, their results in general found their way into the conclusions or recommendations of the HTA reports. Against the background of these results, full HTA reports therefore have the potential to serve translation in the sense of improving the observance of ethical norms or the consideration of ethical issues in practice. This translation is limited, however, because HTA concern rather concrete technologies and, above all, their use in specific countries. This can also be a strength, as "translation" is likely to be more successful the more specific and context-bound it is. Since HTA reports at best bring together the results of the different domains (medical, health economic, social, legal, ethical ...) to reach a conclusion and/or recommendation regarding the use, reimbursement or investment in health technology, ethics is integrated and does not appear as something external to the assessment of the technology. However, the implementation of ethics domains varies greatly in terms of content and quality. Compared to "simple" HTA reports (only medical and possibly health economics domains), few full HTA reports are issued, and they also apparently receive little reception – besides being difficult to find.

Conclusion
To render the possible translation more effective, the international findability of HTA reports with ethics domains has to be improved, and more consensus about best practice approaches in the ethics domain is needed. However, it must be critically questioned how strong the "translation" actually is, especially if one understands translational ethics more as a narrowing of a theory-practice gap – because most HTA ethics domains work with comparatively little theory and are from the outset types of relatively practice-oriented bioethical work. HTA also aims rather at national, regional or institutional decisions than on the practice of individual health care providers. Nevertheless, HTA can be seen as a – hitherto unnoticed? – way of translating ethical information or recommendations.

1.3.1

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Eva van Baarle, Amsterdam UMC & VU University, Ethics, Law & Humanities, Amsterdam, Netherlands
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Avoiding right and wrong. Using a non-normative dialogical ethics support and action research for a normative aim: fostering psychosocial safety.

Strengthening psychosocial safety in the workplace and educational contexts is increasingly prominent within healthcare and teaching programs at medical faculties. Worldwide, the #MeToo movement has drawn significant attention to issues like (sexual) harassment, bullying, and power abuse. A psychosocially safe working and learning environment is not only morally imperative but also essential for fostering interdisciplinary professionalism and a positive learning climate. Furthermore, research indicates that a lack of psychosocial safety in the workplace and educational settings may lead to increased sick leave and employee turnover.

A traditional response to incidents and scandals related to psychosocially unsafe environments typically involves: A) Establishing clear norms that define what is morally wrong and morally appropriate (e.g., within policy documents and codes of conduct), B) Implementing various educational programs and interventions that explain what psychosocial safety means in practice and what behaviours are considered inappropriate, C) Creating a specific reporting structure for employees and students to share negative experiences (e.g., through ombudsmen, confidentiality and integrity officers, or dedicated WhatsApp mechanisms). On average, such responses exhibit two common characteristics: the articulation of clear prescriptive norms and a focus on preventing negative behaviour. Paradoxically, this heightened attention to psychosocial safety can either make people more judgmental of others' behaviour or make employees, especially leaders or supervisors, uncertain about what is currently deemed morally appropriate, such as when giving critical feedback or making jokes.

In response to requests from two clinical wards, the Ombudsman's office (along with confidentiality officers) and our Ethics Support Group (providing clinical ethics support services and CESS research) have developed and piloted an action research program with non-normative dialogical ethics support, comprising two phases: 1) 3 dialogue sessions in a row with fixed groups, and 2) harvesting and initiating suggestions to improve their work- and learning climate. The pilots were accompanied with a baseline survey and post-measurement survey of which the data were shared with the two clinical wards. We are currently starting a new (phd) project for 3 years to further develop the methods for the dialogue sessions, the measurement of (norms related to) psychosocial safety and changes over time, and action-research for fostering an improved psychosocial safety at the wards.

During our presentation, we will first provide a more detailed overview of the ethical rationales of the program and its structure. We will focus on a particular philosophy and perspective on both ethics support and psychosocial safety. We will emphasize the use of the inherent epistemological uncertainty within ethics by prioritizing dialogue and moral inquiry rather than aiming for definitive moral conclusions or moral condemnations of behaviour or persons. This approach can help create a safe atmosphere when discussing sensitive and vulnerable issues. During the presentation, we will share our expriences with the non-normative dialogue sessions, their inherent moral challenges, and some first evaluation results of the pilots.

1.3.2

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Preparing ICU teams for triage during a pandemic: About transdisciplinary development, implementation, and research

Background and Objective
Pandemic triage protocols need implementation at hospitals to ensure applicability and reliability. An analysis of the clinical context is a prerequisite to facing real-world challenges. The PrioPan project (Prioritization of scarce critical care resources during a pandemic) comprised the translation of a national triage guideline into a practice protocol, its evaluation at our University hospital, and the analysis of preparation for pandemic triage in intensive care in Germany.

Methods
We conducted a prospective, mixed-methods simulation study at our University hospital (PrioPan1) and a nationwide qualitative interview study (PrioPan2). The simulation study included a quantitative analysis of ICU patients rated according to their likelihood to survive their acute illness and a qualitative content analysis of focus groups. In the PrioPan2 study, we analyzed one-on-one interviews by phone with fourteen intensivists who were in charge of preparing their institutions for impending triage during the pandemic.

Results
The likelihood of survival to hospital discharge can be assessed by intensivists. The SOFA score and the length of ICU stay were significantly higher in patients sorted for triage. A mortality of 80% confirmed the estimated unfavorable prognoses, but a reliable ranking within this subgroup was not achieved. A consensus-oriented, team-based approach for triage should ensure the best possible care, mitigate potential bias, minimize the risk of discrimination, and reduce the emotional burden for bedside physicians.
Intensivists focused on measures to prevent triage. However, discovering the phenomenon of covert triaging was unexpected. It included decisions such as stricter indicating intensive care and directing ICU admissions, but also limiting treatment in order to keep beds free. It became obvious that interdisciplinary assessments aiming at consistency, and transparent reasoning are required and that ethical guidance should be agreed upon by society and enshrined in law.

Conclusions
In healthcare crises such as a pandemic, where individual and public health are at stake protocols must integrate principles and arguments to balance both individual and public perspectives in order to ensure fair allocation. A legal framework and societal agreements on ethical guidance are prerequisites to prevent non-transparent covert triage.

1.3.3

Francesca Reato, University of Insubria, Research Centre in Clinical Ethics (CREC), Varese, Italy

At Home Ethnography and Interviews to the Double for the construction of the Repertoire of Core Competencies of the Clinical Ethics Consultant in the light of the European and Italian Qualifications Framework

Background/Question
The process of professionalization of the Clinical Ethics Consultant, to be fully realized, requires the public recognition of the Qualification. In the year 2023, the process of building the Competencies Repertoire of the Clinical Ethics Consultant was initiated, according to the criteria recalled by the European Qualifications Framework for Lifelong Learning (EQF, 2008; 2017), using the structuring of the Italian Qualifications Framework (2012; 2016; 2018). Highlighting the qualification's clear connection to EQF levels 7 and 8, we began to describe the learning outcomes of the identified competencies, through knowledges, skills, autonomy and responsibility.

Methods/Materials
In order to reach data saturation, according to the qualitative research approach, an ethnographic study characterized by unstructured in-depth interviews conducted according to the principles of At Home Ethnography and "Interviews to the Double" (Gherardi, 1990; 2001; Oddone et al., 1977; Nicolini, 2009; Gorli et al, 2015) was initiated. At interviewee is asked to imagine that he is to be replaced by a "Double" who will take his place in the performance of work activities, and to provide him with all the indications so that he: a) understands what it is necessary to do from the beginning to the end of the day, at the time when he will replace him; b) no one can suspect the exchange that has taken place.

Results and Discussion
The "Interviews to the Double" have contributed to the identification of Transversal Competencies (1. Leadership; 2. Communication and Interpersonal Relationship; 3. Critical Thinking 4. Problem Solving; 5. Decision Making; 6. Coping With Emotions; 7. Self Awareness; 8. Team Work) and the Advanced Specialized Technical Professional Competencies (1. Ascertaining the nature of uncertainties or moral conflicts requiring ethics consultation; 2. Conducting the Clinical Ethics Consultant process; 3. Encouraging the resolution of uncertainties and moral conflicts; 4. Facilitating the construction of an ethically grounded solution; 5. Documenting planned and implemented ethics consultation; 6. Monitoring the Clinical Ethics Consultation service; 7. Improving the quality of the Clinical Ethics Consultation service). They also offered the possibility of tracing tacit routines put into action and interpreted by each Professional, through the exercise of storytelling of daily micro-actions and practices, including attitudes, emotional and intentional colorings of one's own professional actions.

Conclusions
"Instructions to the Double," in addition to being fundamental to the construction of the Clinical Ethics Consultant's Core Competencies Repertoire, provides an opportunity to "exchange of roles" and know more deeply about the actions and reasons for Colleagues' practices.

1.3.4

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Parents and clinicians' experiences with remote paediatric clinical ethics consultation during the pandemic: A service evaluation.

Though shared decision-making is the norm in UK healthcare ethical deliberations rarely involve patients, including in paediatrics. Recently, both the Nuffield Council of Bioethics and the judiciary have expressed concern about the lack of guidance on parents' participation in ethical deliberations.
Recognizing the importance patient involvement, our tertiary children"s hospital Ethics Case Reviews (ECR) process routinely invites parents and, when appropriate, children to attend. The onset of the COVID-19 pandemic necessitated adaptations to the usual process, leading to remote participation via Zoom.
Aim: This service evaluation explored the experiences and perspectives of both parents and clinicians regarding active parental involvement in ECR during the pandemic, specifically focusing on the novel approach of virtual attendance through Zoom.

Methods
Qualitative service evaluation involving online semi-structured interviews with parents and clinicians who had referred cases for ethics review between March-Dec 2020. Exclusions: Deceased patients, those with ongoing legal involvement or for whom the referring clinician considered it inappropriate to approach them and referring clinicians also on the ethics team. Interviews conducted on Zoom, recorded, transcribed verbatim, and analysed using thematic analysis.

Results
8/14 referrals eligible; 3 families (2 couples and a single parent) and 4 clinicians participated. All ECRs were for consideration of innovative therapies. Qualitative data organised into six themes: (i) Being there is essential with attention to each family"s context; (ii) Preparation is key; (iii) Valued support in complex decision-making process; (iv) Meeting format – Zoom works well but good to have the choice; (v) ECR"s extended benefits; and (vi) A smooth process with areas for improvement.

Conclusions
ECR were highly valued by both parents and clinicians. The active participation of parents in ECR was deemed essential, with need to acknowledge each family's unique context. Guidelines should be developed to ensure the active involvement of parents, and YP where feasible, in ethics processes, emphasizing the importance of adequate preparation from all stakeholders for a valuable and effective review.

1.4.1

Larry Locke, University of Mary Hardin-Baylor, McLane College of Business, Belton, Texas, United States

Cultural Complications of Translating Healthcare Ethics

Cross border healthcare is a growing, global phenomenon. A 2020 estimate sized this marketing at US$65 to 87 billion and involving 20 to 24 million patients. Some national healthcare systems have even begun to show signs of strain from treating cross border patients. Within the EU and EFTA states, a 2023 review of Directive 2011/24/EU reported that a number of countries found it necessary to limit patient inflows because of the impact of cross border treatment on their resources. Mainly outside the EU, healthcare tourism is estimated to be growing at 15–25% per annum. When patients and healthcare providers (and co-providers) come from different countries, their cultural dissimilarities have the potential to undermine a common understanding of healthcare ethics and can complicate ethical translation for practice. This same phenomenon can exist in cross border healthcare research, particularly clinical trials.

Many common ethical frameworks have a strong cultural element. Some formal systems such as Kantianism and Contractarianism are dependent upon social constructs that dictate what is acceptable to individuals within their social context. Even more empirical frameworks like utilitarianism can be dependent upon socially determined evaluations of harms and benefits, and faith-based deontological frameworks are influenced by cultural interpretations of God and sacred literature. These cultural differences can produce divisions in common ethical questions evaluated in different countries, even when those questions are analyzed under the same ethical frameworks. The divisions can lead to misunderstanding and miscommunication in a number of cross-border ethical issues, such as placebo use in pharmaceutical trials, ethical responses to climate challenges, and the ethics of human gene editing. Educational programs for healthcare professionals, or for patients, that fail to uncover and explore these cultural differences can serve to propagate misunderstanding and cultural tribalism. This failure is all the more critical in the present period when the globalizing healthcare industry (and the global nature of many of our ethical challenges) call for common understanding and cooperation.

In this paper, the author explores potential strategies for translating healthcare ethics across cultural boundaries. Being on faculty at universities both in the United States and in Eastern Europe has allowed the author to teach cross listed classes that include students from very different cultural backgrounds. Based on this experience, the author will share some of the most, and least, successful strategies for generating cross-cultural understanding of ethical analyses for individuals from very different cultures.

1.4.2

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Translation of Bioethics Across Cultural Borders: Exploring the Adoption of the Four-Principles Approach in Chinese Contexts

Along the ascent of empirical bioethics, there has been a burgeoning interest in the practical application of bioethics. Central to this discourse is the inquiry into how bioethics can manifest tangible impacts in the real world. Efforts to bridge the theory-practice gap have underscored the significance of contextualising ethical issues within the socio-cultural, economic, and political milieu. This PhD project, which is kindly supported by the Wellcome Trust, delves into the influence of culture through an in-depth examination of medical practice in China.

As part of ethics translation, the role of ethics training in guiding actions is considered pivotal. In China, the ethical training for healthcare professionals is primarily structured around the four-principles approach. However, Western scholars have critiqued Chinese practitioners for perceived shortcomings in the application of these principles. Specifically, within the realm of the principle of respect for autonomy, Chinese patients are often portrayed as constrained in their ability to access diagnoses, lead care planning, and make medical decisions. In this study, I posit that the criticism levelled against Chinese healthcare professionals for purportedly violating the principle of respect for autonomy stems from an incomplete translation of bioethical principles to the particular context. The research investigates the dynamics between Chinese healthcare professionals, patients, and families within the domain of palliative care. As part of the research, empirical data was collected in 2023 via semi-structured interviews with Chinese healthcare professionals. After preliminary analysis, it appears that the translation of the Western four-principles approach into Chinese practice fails to account for sociocultural disparities, resulting in flawed moral justifications of healthcare professionals" actions.

Empirical evidence reveals several key insights. Firstly, Chinese legislation delineates the acquisition of informed consent differently, mandating the obtainment family approval. Secondly, Confucian ethics in China construes the recipient of care under the unit of the family instead of the individual, which challenges the individualistic underpinnings of Principlism. Finally, the Confucian moral duty of filial piety determines an interdependent relationship between individuals and their families. This interdependence is rooted in a mutual and dynamic exchange of power and interests between generations. Elderly parents are cared for by their adult children, with a concomitant transfer of the elder's decision-making authority to their children. This transfer of power thus mandates a moral obligation of care provided by adult children. In the context of medical practices, this family dynamic obligates adult children to speak for their parents as the fulfilment of care duty, and healthcare professionals to defer to the family's collective opinion represented by adult children as respect for the duty fulfilment in family. However, these moral implications are overlooked by the framework of Principlism.

In conclusion, the critique of Principlism is predicated on its failure to account for local socio-cultural contexts in China. The translation of Western bioethics thus falls short of transcending cultural boundaries, prompting inquiries into the validity of statements derived from this theoretical framework. Accordingly, this project advocates for the indigenisation of current four-principles-based ethics training in China. Integrating local customs, policies, and legal frameworks into the structure of ethics training is expected to enhance the applicability of Western ethical theories to the environment of medical practice in China. Consequently, a revised training curriculum would be more practically pertinent to the work of Chinese healthcare professionals. Through such an approach, the translation of bioethics can be completed within culturally sensitive practices.

1.4.3

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Mourning of spouses after deep and continuous sedation until death: ethical issues of a dialogue between medicine and society, in the french context

Background and issues
Deep and continuous sedation until death (DCSUD) is a practice utilized, among other sedative practices, in palliative care to alleviate the suffering of terminally ill patients. In France, this practice is framed by the law of February 2, 2016, but remains, in practice, little evaluated, both from a clinical point of view and in terms of its effects on the experience of the patient, the team and their loved ones. For example, long-term support for serious illness has been documented as having an impact on the bereavement of loved ones, who are at greater risk of bereavement complications. However, among these relatives, the role of the spouse, most often identified as the family caregiver, remains largely undocumented: how do sedative practices, and in particular deep and continuous sedation, affect spouses' mourning?

Method
To explore this question, the AfterSedatio study, conducted in France, is an interdisciplinary study (psychology, medicine, philosophy, ethics) set out to explore the experience of bereavement for spouses. It uses a mixed longitudinal approach to explore the consequences of bereavement for people who have lost their partner to cancer following a DCSUD.

Results and discussion
The spouses' interviews show the need to focus on these specific experiences of bereavement and the support needs they raise. In the continuity of a couple's relationship and history of illness, the mourning of spouses confronted with sedative practices presents the specificities of experiences of guilt, responsibility, but also doubt or unease during support. The breakdown in communication with the loved one, as well as the impression of having participated, in one way or another, in the decision-making process, call for singular ethical attention. Indeed, these bereavements are also largely influenced by the quality of communication with the care team, which plays a major role in the factors identified by spouses as complicating bereavement.

Perspectives
The ethical issues involved in the decision-making process are complex, mobilizing not only the support time (before, during and after), but also the various players involved in the situation. In this respect, the attention paid to spouses aims not only to shed light on their experiences throughout the support process, but also to identify points for transforming practices, so as to continue to place the ethical issues of end-of-life and bereavement within a social and political framework.

1.4.4

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Interdisciplinarity in bioethics and associated challenges

Question
The theme of this conference is Translating Ethics into Healthcare Practice and Research. Thereby, the conference highlights new developments in bioethics that can be coined under the term Translational Ethics. A key methodological and conceptual characteristic not only of the practice-oriented subfield translational ethics but also of bioethics from its early days in the second half of the 20th century until today, is its interdisciplinarity. This talk focuses on the question: Which challenges are associated with interdisciplinarity in bioethics and translational ethics?

Methods
Following a brief description of the indispensability of interdisciplinarity – for which there might be an even greater need in translational ethics than in bioethics as a whole –, two sets of challenges related to interdisciplinarity in bioethics are described. The challenges are illustrated by experiences of the speakers, who have been working in translational bioethics for several years. Particular attention is paid to challenges associated with interdisciplinarity in projects carried out under time and resource constraints.

Results
The first set of challenges concerns knowledge acquisition, transfer, and communication. The challenges are illustrated by examples drawn from a research project we worked on, where the ethical implications of epigenome editing were compared to genome editing in healthcare research. One of our experiences is that translational ethics on a topic such as epigenome editing, which is only emerging in science and is largely still unrecognized in bioethics, is especially time-consuming. The early stage of epigenome editing research, required – even more in this project compared to our experiences from other projects – to deeply dive into debates and search for experts outside our own discipline (e.g., epigeneticists) who could help us understand the ethical implications of epigenome editing. This also meant that we had to translate insights from epigenetics research to the bioethical community before we could translate ethics into epigenome editing research, which came with its own translational challenges.
The time-consuming acquisition and translation of knowledge between disciplines ties the first set to the second set of challenges regarding interdisciplinarity in bioethics. The second set of challenges concerns research funding and academic qualifications. A time-consuming knowledge acquisition and translation phase conflicts with time constraints of projects funded only for a few years. An underlying problem might be the financial dependency of bioethical research on third-party funders. Further challenges associated with interdisciplinarity of bioethics and related to funding result from missing standards for what "good" interdisciplinary research is, a challenge for objective evaluation of research proposals. In addition, new challenges for the acquisition of academic qualifications emerge from differences in academic cultures (e.g., authorship conventions). Moreover, we identify as a challenge the potential emergence of an entirely new career stage: scholars work interdisciplinary for some years in between different career phases, e.g., between a Master degree and joining a doctoral program or for a substantial amount of time after completion of a doctoral program. The challenges this comes with are not unique for bioethics, but the emergence of these potential new academic career stages is, in our experience, most prevalent in interdisciplinary research and even more so in the ethics of life sciences because of an interest of funding organizations in projects with an ethical component for which ever more academic personnel conducting that research is employed in fixed-term contracts.

Conclusions
Translational ethicists from various disciplines should work together to develop solutions to the challenges we described. First ideas for solutions are presented at the end of this talk.

1.5.1

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Hospitals as morals actors with institutional duties

Background

Most classical medical ethics theories focus on the role of physicians as moral actors and their part in the patient-physician relationship. However, in the context of patient care in hospitals, there are morally relevant aspects that cannot be attributed to actions or responsibilities of physicians but depend on multi-dimensional organizational structures. Hospitals as organizational entities play a key role: They shape the structures of everyday clinical life, e.g. by implementing incentive systems for employed professions (physicians and nursing staff) and clinical departments, selecting new department heads and other senior staff and making far-reaching decisions on investments, infrastructure development and specialization in clinical care and research. Much of the theoretical debate on ethics of healthcare organizations takes a procedural-discursive approach, focusing on how healthcare organizations can and should establish internal spaces and procedures for ethical reflection, awareness, and discourse of employees within the organization. Beyond that, important questions about the nature of hospitals as moral actors and their moral duties remain neglected.

Research questions

What are the moral reasons why hospitals should promote internal structures allowing for ethical discourse and reflection? Is that a moral duty of hospitals? Can hospitals have moral duties, are they moral actors? If so, what are their basic moral responsibilities and duties?

Approach

In our talk we discuss three questions: (1) Can hospitals be considered as moral actors and thus as subjects of moral duties and responsibilities? To answer this question, we will refer to insights from the business and organizational ethics and adopt reflections on the moral status of companies and organizations. (2) Since we argue that hospitals can and should be seen as moral actors, we analyze what basic responsibilities and moral duties they have. Here, we follow a reconstructive stakeholder approach, that starts with the definition of overall tasks and roles of hospitals in society. From this, we deduce role responsibilities that correspond to morally justified rights and expectation of stakeholders towards hospitals. (3) We will illustrate the relevance and concrete meaning of the basic duties for ethically sound behavior of hospitals in concrete cases, using the following example: What do the basic duties tell us about the moral legitimacy of hospitals using financial incentivize in employment contracts that encourage heads of department to reach certain numbers of surgeries?

Discussion

Although hospitals are not human beings, we consider them to be moral actors because they define organizational goals, plans, interests, and roles that are put into practice by their employees. Thus, hospitals act through their employees. Consequently, they can be attributed moral duties to be carried out by these employees. The basic duties of hospitals include the duty to provide their patients with state-of-the-art treatment; the duty to society including potential future patients to use scarce resources economically; the duty to promote public health; the duty towards their employees to create an appropriate working environment that enables them to work in accordance with their professional ethical standards.

Conclusion

Our approach offers a conceptual foundation and moral framework for how hospitals should shape the structures of clinical practice and on how they should behave towards their stakeholders. It offers a foundation for hospitals to shape and formulate a moral self-image, which can be set out in ethical mission statements to which clinics bind themselves as a kind of self-commitment.

1.5.2

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Codes of Conduct Should Help (Biomedical) Scientists Navigate Societal Expectations

To what extent can (or should) society's values influence biomedical sciences? On the one hand, many pro-social values are virtually universally considered beneficial to society and unharmful to science. For instance, the values of public health and respect for participants, especially those from vulnerable groups, are widely accepted as legitimate. On the other hand, recent calls to anticipate potential socio-political interpretations of research could make scientists self-censor sound results even in the absence of clear and immediate harm. For instance, a recent *Policy Forum* in *Science* asks researchers to anticipate how policy- and law-makers will interpret the use of the terms "sex" and "gender" in scientific articles; similarly, *Nature Human Behaviour* calls for researchers working with human subjects to consider potential harm to broader population groups (not only to the participants of a study). In these cases, there is no single and easy way to weigh immediate scientific loss (not publishing sound results) against the risk of alleged future harm (possible misinterpretations of scientific terms or stigmatization of vulnerable groups). Thus, scientists acting on these calls are bound to face complex ethical-epistemic trade-offs. Scientists should not be left alone in making such decisions and codes of conduct for research integrity can offer invaluable help in this task. Unfortunately, current codes eschew meaningful guidance on how to weigh possibly conflicting values against the aims of science. Even the newly revised *European Code of Conduct for Research Integrity* (ECoC, 2023) is a missed opportunity in this regard.

In this talk, the first author will present our argument for codes of conduct to broaden their scope to include guidance on the trade-offs that professional scientists face when incorporating socio-political considerations. Our argument comprises two parts: the diagnosis of the problem and our positive suggestion on how to go about it. The problem will be first diagnosed by discussing examples of how the trade-offs implied by calls for incorporating pro-social values in science are not easy to solve. Then, evidence will be provided that codes of conduct (ECoC in particular) do not yet offer researchers the proper ethical tools to perform such evaluations. Hence the conclusion follows that future codes need to improve on this.

The positive part of our argument starts with by acknowledging that the decisions scientists are supposed to make are so complex and context-dependent that a one-size-fits-all solution is unlikely to be found. Thus, codes should not try to offer scientists a single rule to be applied in every case but rather endow them with appropriate *ethical-epistemic tools to make decisions themselves.* Accordingly, we focus on how to *effectively translate this into actionable guidance*. First, codes of conduct should bring the *attention* of scientists to the trade-offs they are expected to perform. Second, guiding questions should be developed to make sure scientists *construe* new requirements in appropriate ways. These questions will help researchers actively reflect on how social responsibilities are accounted for and whether this may impact the quality of the research. Finally, the *motivation* behind value integration must be clear and shared by scientists. Calls like the ones mentioned above are based on pro-social goals: these must be clearly conveyed in codes so that the underlying rationale can be understood and expectations of value integration are not perceived as a form of interference. This is difficult to achieve and can be contentious: scientists might genuinely disagree with such calls. Adding a line in a code of conduct by itself is not sufficient to ensure the motivation of scientists: further changes in education, journal publishing, and science funding are due. For this to be effective the active involvement of scientists themselves in the development of such changes must be sought.

1.5.3

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Post-trial care in gene therapy clinical trials: ethical implications and their potential impacts on scientific research

Gene therapy approaches regularly cause irreversible genetic changes. If gene therapies are tested in clinical trials, this raises the question of how the post-trial care of trial participants should be organised, considering both medical and ethical aspects. In the context of post-trial care, interests in research that is as unrestricted as possible can stand in opposition to the interests of the participants.

Legally binding requirements for post-trial care can be, or be perceived as, an obstacle for scientific stakeholders when planning gene therapy studies. If these stakeholders are obliged to take care of medical aftercare and other financial risks, the extent of which is difficult to predict, this can reduce the opportunities and incentive to conduct such research. Nevertheless, the principle is ethically imperative in gene therapy research. Follow-up care must be guaranteed both in the case of positive effects of gene therapy treatment that lead to an interest in continued provision of the trialled therapy on the part of the person treated and in the case of unforeseen negative side effects of a physical or psychological nature. This should be covered by the actors carrying out the treatment, as the costs incurred should not be borne by public healthcare systems or even the participants themselves.

This contribution will first present and analyse various ethical concepts of post-trial care. In addition to the common idea of post-trial access, which is already taken into account in the Declaration of Helsinki, the provision of psychological care or the facilitation of alternative medical care will also be examined. These aspects are becoming increasingly relevant in the field of gene therapy, as the genetic modifications induced in the test subjects cannot usually be reversed. In contrast to studies on conventional medicinal products, it is often impossible to restore the pre-trial physiological state. For people who take part in such a study, this can reduce the probability of success of other gene therapy treatment methods at a later date. In addition to dealing with the ethical concepts, the extent to which these are considered in existing national and international legal sources and, if necessary, the scope for further development approaches will be analysed. Finally, the potential effects of ethical and legal requirements on research dynamics will be discussed. In addition to the difficulty of planning for the actors carrying out the research, the potentially increased participation rates associated with improved planning security will also be analysed.

Post-trial care should not be orientated towards a medically necessary minimum, instead it should ensure that subjects receive care that goes beyond this. Particularly in the context of gene therapy methods, this is essential and must be taken into account in the study design. Observing ethical implications in post-trial care can also promote the social acceptance of clinical trials in general and the application of different forms of gene therapy in particular. This is another reason why a legally binding consideration of the concepts is to be advocated.

1.5.4

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An ethical argument to limit financial incentives to clinical trial participants

Randomized controlled trials are central to progress in medicine, but trialists commonly struggle to recruit enough participants. Recruitment problems may lead to the termination of trials, thereby exposing participants to needless risks, wasting valuable resources, and undermining medical progress. Financial incentives are one proposed solution, but they can undermine the autonomy of potential participants raising questions regarding their ethical permissibility. While some have dismissed this worry about financial incentives and argued that we should be paying participants more to avoid exploitation, we argue that there are good reasons to keep financial incentives to research participants low. We conclude that, while small sums of money are permissible as incentives, larger financial incentives should be avoided.

We first argue that exploitation claims do not apply to financial incentives. Largent and Fernandez Lynch have argued that participants are exploited when paid too little. This, we argue, conflates different types of payments to participants. Unlike reimbursement of expenses and compensation for time and burdens, financial incentives are not payments to which participants can have a claim and, therefore, fall outside the scope of exploitation arguments.

The ethical permissibility of financial incentives turns on different conceptions of "undue influence". The term "undue inducement" is commonly, including by Largent and Fernandez Lynch, used to refer to the worry that large incentives cause potential participants to take on risks that they should not take. On this interpretation of undue inducement, there is indeed little reason to limit financial incentives. But we argue that another, often overlooked, conception of undue influence gives reason to limit the financial incentives to trial participants. A financial incentive is also an undue influence when it causes people to enroll in a trial even though they would rather not participate. Since large incentives can be irresistible for people who would otherwise not participate and, thus, result in involuntary participation, they can be an undue influence. This risk of involuntary participation is a reason to be careful with large financial incentives and keep incentives low for everyone.

Large financial incentives can also result in an unjust distribution of the burdens of research participation. Large sums of money could disproportionally incentivize people from socially marginalized groups to participate, who would, consequently, carry the burdens of research, while being less attractive for the rich, who would also benefit from medical research. Proponents of large payments have objected that larger incentives will contribute to a more just distribution of the burdens of research by incentivizing the rich, who would not participate for smaller sums of money. Empirical research does not yet show which of these two hypotheses is correct. Because of the injustice of placing burdens of research on the poor and the current demographics of professional research participants, those who claim that larger payments will lead to a more equitable distribution of research risks have the burden of proof, which is currently not met. Without empirical data, we should err on the side of caution and keep financial incentives small.

Based on these concerns about voluntariness and justice, we conclude that small financial incentives to trial participants are permissible, but we should not give large financial incentives to participants. Incentives should, therefore, not exceed €70. This €70 limit is a preliminary, and admittedly somewhat arbitrary, threshold. More empirical data on the effects of financial incentives in real trials is necessary to further specify and justify this threshold. To get these insights, it is important that trialists that use financial incentives keep track of important data, such as the demographics of their participants and retention rates.

1.6.1

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The Gap Between Theory and Practice: Blurring Boundaries of Current Consent Approaches in Health Research Practice

Background
Given the rapidly evolving landscape of health research in the digital age, one important question for ethics in healthcare 4.0 is if and how concepts from ELSI debates can appropriately be translated into actual research practice. We argue that one topic where this is particularly pertinent is that of patient consent in data driven health research. With the upcoming of biobank-based research and, more recently, secondary research use of patient data from larger data sharing infrastructures, novel models of consent such as broad consent, dynamic consent and meta consent have entered scholarly debates. ELSI researchers thoroughly discuss the ethical pros and cons of these models as well as their legal and ethical legitimacy. However, we argue that current consent practices partly elude the consent models as conceived and discussed in theory.

Research aim
This talk has two aims. First, providing a characterization of various consent approaches used in current research practice, we highlight how conceptual distinctions from theoretical discussions can become blurred, and we emphasize that actual consent approaches are more heterogeneous and complex than suggested in theory. Second, we explore the implications and consequences thereof for ethical theorizing about consent and its translation into health research practice.

Discussion
From our experience in several big and nationally leading initiatives such as the German Medical Informatics Initiative (MII), we illustrate some examples of recent consent approaches that elude widespread theoretical conceptualization:
a) The MII uses a broad consent approach and offers an openly accessible transparency platform that lists research projects before their start and before they are warranted access to patient data. This partly blurs the lines between broad and dynamic consent as it enables patients to express in advance their unwillingness of having their data shared with specific research projects.
b) Furthermore, a template has been developed for combining the MII broad consent with informed consent forms from clinical trials, asking patients for permission to broadly reuse data from these trials for secondary research purposes. Here, informed and broad consent forms are integrated into one (new sort of) consent.
c) Another related development in the MII is the integration of additional consent modules into the MII broad consent form, asking patients to allow researchers to collect additional data through limited further research interventions – the latter of which are usually subject of specific informed consent approaches.
d) Within of what will be the most important German network of oncological clinical trials, it is planned to recruit patients for research by offering them two consent forms in a row: an informed consent for participation in a clinical trial and a broad consent for the secondary research use of the trial data and clinical care data. This approach closely links two distinct consent approaches in one overarching sequential consent process.
The examples illustrate that current consent approaches partly elude the consent models discussed in theory, and that new approaches emerge that have not been conceptualized so far. Thus, ELSI researchers should study the intricacies of actual consent practices and carefully evaluate how existing conceptual categories are suited to address these intricacies. Furthermore, governance bodies such as IRBs should be attentive to the evolving landscape of consent approaches and to how these approaches may spark novel difficulties. For example, the combination of consent forms can give rise to inconsistencies or ambiguities that require ethical analysis.

Conclusion
Some new consent approaches in practice diverge from concepts of consent models widely used in theory. It is important for researchers and governance bodies to recognize the complexities of such approaches and evaluate the ethical implications thereof.

1.6.2

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Patient preferences in geriatric wards, a survey of health care professionals' practice, experience and attitudes

Background
Assessing patients" preferences may identify important health outcomes and value their perspectives. We aimed to identify whether health care professionals (HCP) in geriatric wards examine their patient and next-of-kin preferences for information, involvement, and treatment, and to study whether medical decisions consequently follow these preferences.

Methods
We conducted a cross-sectional web-based survey with multidisciplinary HCP from 12 South-Eastern Norway Regional Health Authority geriatric wards. First, we examined whether HCP clarify the patient preferences. Second, we investigated the experiences of clinical practice in accordance with these preferences. Third, we explored HCP"s attitudes towards who makes and who should make clinical decisions. We recorded HCP"s age, sex, profession, years in clinical practice and experience as a leader. We used SPSS v 29 for descriptive analysis.

Results
We received response from 289 HCPs (attendance rate 61 %), with mean age 37.8 years (SD 11.3), 235 (81.3 %) women, 12.4 (SD 9.6) years of experience and 67 (23.2 %) MDs.
In total, 192 (66.4 %) sometimes/never clarified the patient preferences for information, 160 (55.4 %) for involvement and 125 (43.3 %) for treatment. HCP reported that 178 (61.6 %) and 142 (49.1 %) sometimes/never clarify preferences for information and involvement of next-of-kin.
Secondly, 191 (66.1 %) do not follow patient preferences for information; either because patient preferences are unknown, or they choose to inform more or less than wanted, 154 (53.9 %) do not follow the preferences for involvement and 151 (52.2 %) do not follow the preferences for treatment, with similar trends towards next-of-kin.
Only 115/164 HCP (70.1 %) follow the clarified patient preferences for treatment. Interestingly, 23/125 (18.4 %) report conducting treatment in accordance with the patient preferences without clarifying them.
Thirdly, 61 (21.1%) report that HCP make the decisions alone, while only 13 (4.5 %) think they should. Interestingly, 153 (52.9 %) think that HCP, patients and next-of-kin should make decisions together, while only 74 (25.6 %) report this integrated in their current clinical practice.

Conclusions
As only half of HCP report clarifying patients" preferences and the majority not informing, involving and treating in line with such preferences, there seems to be a lack of awareness towards assessing and including patient preferences when providing healthcare. However, since they believe that HCP, patients and next-of-kin should make clinical decisions together, our findings may indicate motivation for a more person-centered approach.

Publication
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1.6.3

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Should Aspects of Environmental Sustainability be Included in Health Counselling? A Systematic Review of Reasons

Question
The escalating climate crisis is affecting the health of individuals and communities, with the health sector accounting for up to 8.5% of national greenhouse gas emissions in the case of the US. With some scientific reports suggesting that global warming has already exceeded 1.5°C above pre-industrial levels, new approaches to healthcare are needed to mitigate this crisis. Much can be done at the meta-level (e.g. government ministries of health) and meso-level (e.g. hospitals) of the health system, but also at the micro-level (e.g. medical consultations). Health professionals in direct contact with patients, such as psychologists, nurses and doctors, have a particular opportunity to address the climate crisis in clinical encounters. This can be done by incorporating environmental sustainability considerations into health counselling, also framed as climate-sensitive health counselling, green informed consent, or as a clinical discussion with a patient about green prescribing. However, from a medical ethics perspective, it is unclear whether health professionals should give this kind of advice, even if it is possible to do so. There are limits to translating climate ethics into direct patient care. For example, patient autonomy and beneficence are two well-established biomedical principles that may argue against considering environmental consequences in medical consultations.

Methods
We conducted a systematic review of reasons on whether healthcare professionals should include aspects of environmental sustainability of medical interventions in health counselling. Pre-registration was done using Open Science Framework [https://osf.io/qmy4b]. The databases Pubmed and Web of Science were searched for articles published until 8 January 2024, with no restrictions on article type. Data analysis was performed according to Kuckartz" main principles of qualitative content analysis using MAXQDA2020.

Results
The search identified 1669 articles. Title-abstract screening was performed using predefined inclusion and exclusion criteria. 71 articles, mostly opinion pieces, commentaries and research or review articles, were included in the full text analysis. Reasons for and against the implementation of environmental sustainability aspects in direct patient contact were found. The results highlight the breadth and complexity of the considerations of climate-sensitive health counselling. When the options discussed in the clinical encounter have a negative impact on the climate, the debate becomes even more controversial and philosophically interesting. Preliminary findings include that the established doctor-patient relationship and the personal views of the patient are an important aspect of whether or not climate-sensitive health counselling should be used. It should be noted that the scientific discourse has not yet agreed on a term to describe this type of intervention. Furthermore, it is unclear at the conceptual level how to distinguish the different approaches (climate-sensitive health counselling, green informed consent, green prescribing, etc.). The indexing of articles in the area covered by this systematic review is rather underdeveloped. It was therefore methodologically challenging to find all relevant papers.

Conclusions
This systematic review provides a comprehensive overview of the variety of ethical reasons for and against the inclusion of environmental sustainability issues in health counselling, and highlights the conditionality of different factors. This work can provide a basis for further bioethical debate and clinical practice.

1.6.4

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Assessment of decisional capacity. A systematic review and analysis of instruments regarding their applicability to requests for assisted suicide

Question

Decisional capacity is an important requirement for ethically and legally justified assisted suicide. A widely used definition of decisional capacity generally includes four criteria: understanding, appreciation, reasoning and expressing a choice [1]. In clinical practice, decisional capacity is often assessed as part of an unstructured interview [2]. Evidence indicates that this practice can lead to heterogeneous results depending on the clinician and other factors [3]. While several instruments have been developed to assess capacity to consent to treatment, little is known about their applicability to assessing decisional capacity for assisted suicide.

Methods

Based on a systematic review by Amaral et al. [4] of instruments assessing capacity to consent to treatment published up to 2018, we updated the search for instruments up to October 2022. For all included instruments, data concerning criteria for determining decisional capacity covered by the instruments, psychometric properties and procedural aspects were extracted. Secondly, all instruments assessing decisional capacity by utilising at least all four criteria proposed by Grisso and Appelbaum [1] and in relation to a specific decision were analysed regarding their applicability to requests for assisted suicide.

Results

We identified 23 assessment instruments for capacity to consent to treatment. While every instrument included some or even all four criteria defined by Grisso and Appelbaum [1], a more detailed analysis indicated that operationalisation of these criteria varies between instruments. In addition, some instruments incorporated further criteria for assessing decisional capacity. In line with further inclusion criteria, five instruments were assessed for applicability to requests for assisted suicide. Analysis shows several limitations in this respect. Most prominently, the framing of decisional capacity within the context of illness and treatment options and the lack of flexibility to adapt proposed items to assessing decisional capacity for assisted suicide could be identified.

Discussion

In our presentation, we will describe in detail the potential as well as the limitations of utilising existing instruments to assess decisional capacity for situations in which persons request assisted suicide. We will focus our analysis on the judicial context in Germany, according to which the right to assisted suicide is based exclusively on the right to self-determination which includes decisional capacity [5]

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2.2.1

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Parkinson's disease patients with Deep Brain Stimulation (DBS): A qualitative exploration of evolving experiences over time

The integration of neurotechnologies into clinical settings presents a compelling challenge to translational ethics in healthcare, especially within the landscape of the fourth healthcare revolution, which advocates accelerating medical innovation while improving the effectiveness of patient care. Deep brain stimulation (DBS), a neurosurgical intervention now established as the standard of care for advanced stages of Parkinson's disease (PD), constitutes an interesting area of investigation for evaluating the successes and challenges associated with implementing patient-centered care in the healthcare 4.0 scenario.

While DBS is recognised as an effective therapeutic intervention for carefully selected patients, understanding of its effects extends beyond motor improvements to include psychological and psychosocial dimensions with implications for long-term quality of life, areas that remain relatively underexplored. Research on the long-term outcomes of DBS in PD predominantly relies on metrics such as therapeutic efficacy and motor-related endpoints. However, this approach falls short of providing a comprehensive assessment of patients' daily functioning over extended periods of time.

The post-DBS phase introduces distinctive challenges in patients' lives, requiring individuals to adapt to a novel therapeutic device and to manage the emergence of new disease symptoms and stages. This transformative shift in patients' reality imposes new reflections for decision-making that extend beyond the initial treatment considerations. Given the profound impact of a person's experiences, beliefs, expectations, and perceptions on physical, psychological, and social dimensions of health, patient care must move beyond the confines of the disease to a more holistic approach that includes other structural dimensions of health.

This study aims to delineate the needs, expectations, and perceived outcomes of patients on one hand, and concurrently, scrutinize the blind spots, ethical concerns, and deficiencies in the care provided to patients throughout their journey with DBS. This is achieved through a comprehensive qualitative analysis of patient interviews before and at various intervals after the DBS intervention. This approach also contributes to constructing a chronological timeline detailing patients' experiences and valuing their narratives as an integral component for assessing the overall success of the treatment.

The results offer insights into the nuanced experiences and ethical dimensions of long-term DBS by identifying congruent or divergent thematic patterns across participants' subsamples. The outcomes contribute to a comprehensive understanding of the challenges and considerations associated with DBS, thereby empowering sustained informed decision-making throughout the entirety of the DBS journey for clinicians, researchers, and most importantly patients and their families.

2.2.2

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Non-voluntary BCI Explantation: Assessing Possible Neurorights Violations in Light of Embedded and Extended Cognition

Since in research involving patients with implantable neural interfaces there is a regulatory gap concerning post-trial responsibilities and duties of sponsors and investigators towards these patients, we propose to define them in light of their neurorights, which are fundamental human entitlements related to the brain and mind (Ienca 2021). Moreover, since the degree and strength of post-trial moral responsibilities also depends on the degree of patients" vulnerability (Sierra-Mercado et al. 2019), we evaluate whether interpreting the BCI as a constitutive component of the mind of implanted patients implies an additional level of vulnerability in case of neurorights violations. According to the theory of extended cognition (EXT), given specific coupling conditions a device can be considered as a material component of the supervenience base of a person"s mind. In contrast, an internalistic and embedded view of cognition (EMB) considers non-biological components merely as external causal supports for the implementation of brain-based cognitive capacities. Thus, we evaluate whether and how EMB and EXT imply morally relevant differences in interpreting the neurorights of implanted patients and the corresponding responsibilities and duties of sponsors and investigators.

Thus, we use these theoretical frameworks to assess on a descriptive and moral level of analysis the real-world medical case report of patient R, who was implanted with an advisory BCI system to detect and predict epileptic seizures. After years of successful use, the device manufacturing company went bankrupt, hence was no longer able to guarantee continuous support in case of battery depletion, software update, and recalibration. Thus, patient R was pushed to undergo a non-voluntary explanation, which caused her serious psychological and mental harm, such as a discontinuation in her sense of agency and sense of self (Gilbert et al. 2023).

On a descriptive level of analysis, we consider Heinrichs" (2021) dimensions of cognitive integration between R and her BCI in light of her phenomenological structured report, according to which she felt it as a part of her self (Gilbert et al. 2023). The device directly contributed to shape patient R"s agential planning, self-regulation and decision making, by predicting and alerting R of incoming epileptic seizures, enabling her to take appropriate medication. Given the high degree of cognitive integration, we conclude that patient R can legitimately be considered both as an embedded and an extended cognitive agent.

Then, we evaluate on a moral level whether the non-voluntary explantation violated patient R"s neurorights, how this violation can be differently interpreted in terms of EMB and EXT, and the different subsequent moral responsibilities that EMB and EXT give rise to sponsors and investigators.

First, we argue R"s negative right of not having a device explanted against her consent is practically cancelled if not accompanied by the right to receive continuous technical support. Given that the absence of continuous support would have exposed the patient to potential harms, such as infection, from a moral perspective patient R had no choice but to undergo non-voluntary explantation. This form of implicit coercion violated her personal autonomy, right to bodily integrity and eventually her neurorights. We argue that R"s right to cognitive liberty, mental integrity and psychological continuity were violated either if we embrace EMB or EXT.

By considering the fundamental human entitlements captured by these neurorights, we conclude that EMB and EXT give rise to moral responsibilities and duties with the same scope to sponsors and investigators, who must guarantee continuous technical support to the implanted BCI to respect these entitlements. In addition, EXT strengthens this obligation of not to deprive implanted patients of a constitutive component of their minds and to maintain its functioning.

2.2.3

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Hybrid Minds: Experiential and ethical implications of intelligent neural interfaces

The rise of a new generation of intelligent neural interfaces, including closed-loop and neuroadaptive technologies, hastens the clinical deployment of brain-computer interfaces (BCIs) to treat neurological and neuropsychiatric disorders and bridges the gap between clinical neuroscience and medical artificial intelligence. They afford a novel form of human-machine interaction between the human brain, the mind, the neuroprosthetic hardware and the self-learning algorithms, and other artificial intelligent components that operate them. We call the result of the interaction and functional integration of these components the "hybrid mind". However, it remains unclear what impact, if any, such intelligent components may have on the subjective experience of their users. Using Thomas Nagel's famous wording we could say that it remains unclear to scientists "what it is like" to have a hybrid mind.

In our study we therefore conceptualized the novel phenomenon of hybrid minds, identified the ethical and legal challenges arising from hybrid minds, and explored the experiences of users of clinical neurotechnology. To this end, we explored the experiences and attitudes of patients using non-invasive therapeutic neuromodulation for psychiatric disorders as well as patients receiving invasive treatment via Deep Brain Stimulation for neurological conditions. This presentation will provide an overview of the key results at the conclusion of our three-year study, enabling an empirically grounded and technologically informed ethical analysis of normative questions posed by intelligent neural interfaces.

2.2.4

Marta Vassallo, University of Insubria, PhD program in Clinical and Experimental medicine and Medical Humanities, Varese, Italy
Mario Picozzi, University of Insubria, PhD program in Clinical and Experimental medicine and Medical Humanities, Varese, Italy
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Assessing Cognitive Enhancement

Enhancing one's own cognitive abilities is a goal of many groups of healthy individuals, especially when considering people with highly stressful jobs, students, and other clusters of healthy people looking for some enhancement in order to be more focused, efficient, and less tired. This necessity can be related to our current times where productivity is the most important value in the workplace, nonetheless, this need is absolutely real, and it must be addressed and documented both by research and medicine. For these reasons, cognitive enhancement is an extremely vast and interesting topic in neuroethics. However, its specifics and details are often vaguely described within the existing literature, especially regarding pharmacological enhancement, which can be considered a high-risk practice. For these reasons this work aimed at systematizing enhancement as a neuroethical concept, by clearly defining its three macro areas: pharmacological enhancement, neuro-hacking, TCS, and other kinds of external stimulation and analyzing the related problems and perks. Another question we aimed to answer is "What is stimulated?", of course, this issue is largely controversial, and by analyzing the existing literature we attempted to assess the focus areas for enhancement concerning each specific kind of enhancement. Finally, our focus shifted again to a comprehensive bioethical analysis and discussion, considering the classical issues of autonomy, beneficence, non-maleficence, and justice, and analyzing them within the specific context of neuroenhancement.

In the end, we found that some kinds of enhancement have decidedly fewer risks and create fewer issues in a bioethical context, and for this reason, they are preferable.

2.3.1

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Ethical competencies for digitally supported care

Background

Digitalization in the care sector, which is still in its infancy, will increase significantly in the coming years. In order to participate actively, nurses need to be adequately trained for the demands of digitalization. Due to the real proximity of nursing actions to ethical issues, the teaching of digital skills must always include ethical skills. It is therefore important to design a targeted training program that includes ethical skills and to evaluate its effectiveness.

Research question

How does the continuing education measure “Consultants for digital health care” affect the ethical skills development of the participants?

Method

The recording of the learning impact of the ethics module of the further training follows a mixed-method design. In the quantifying part, the self-assessment of ethical competence of the participants will be measured by a questionnaire using the validated test instrument of the “Ethical decision-making confidence scale for nurse leaders” (EDMC). In the qualitative part, twelve semi-structured, problem-centered, guided interviews will be conducted. The aim of this exploratory study is to uncover meaningful relationships in the area of increasing ethical competence.

Results

A large number of EDMC items show a significant increase as a result of the intervention. Particularly high increases were found in the following areas: 1) articulating the definition of moral distress and providing an example of their experience of moral distress in their practice, 2) applying ethical decision-making models or structured processes to complex clinical problems, 3) participating in and/or leading mediation related to complex clinical problems involving ethical dilemmas or moral distress.
These results are confirmed by the interviews, as the participants report on what they have learned, express the need for teaching ethics in nursing, and their willingness to consider ethical aspects in the use and implementation of technology. In particular, the following points were emphasized: 1) Increased awareness of the ethical dimension of one’s own professional actions, 2) Use of models for ethical reflection in the use of digital technology, 3) Ethical sensitivity in the use of digital technology, 4) Willingness to consider ethical aspects in the use and implementation of technology.

Discussion

In light of the results, an increase in ethical competence can be observed as a result of the training intervention. The participants showed a high level of awareness and immediately implemented the content of the training. The question remains to what extent a link can be established between subjective self-assessments and objective measures of ethical competence. The results of this study will be used to develop appropriate instruments. The extent of empirical information on digital technologies needed for an ethically competent judgement and action and the relationship between ethical and digital competence needs to be further explored.

2.3.2

Katja Kuehlmeyer, LMU Munich, Institute of Ethics, History and Theory of Medicine, Munich, Germany
Tobias Eichinger, University of Zurich, Institute of Biomedical Ethics and History of Medicine, Zurich, Switzerland
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Translating ethics into practice through competency-oriented teaching and learning: Experiences from the German KOMETH-Learn project

Ethics teaching for health professions and disciplines should not only aim to impart knowledge, but above all to give students the opportunity to acquire competencies for their future professional activities. Ethical competencies consist of the abilities to align professional action with and reflect on professional ethical standards. Furthermore, they include the abilities to identify an ethical question or problem, to take different perspectives on issues, to make sound ethical judgments, and to realize an ethically justifiable action in practice. Such competencies are key for the implementation of a professional practice which is oriented towards ethical requirements.

Lecturers and teachers who are interested in competency-oriented teaching in the education and training of health professions need to be able to choose competence-based learning objectives, suitable didactic methods and tasks for assessing the skills level of students. Furthermore, they need to evaluate their learning arrangements with regard to their aims, which requires performance tests that assess underlying competencies. However, the required fundamental teaching skills neither have been described sufficiently in this field nor have they been taught in a structured manner, yet.

In the German-speaking countries, for example, very few articles or books are concerned with the didactics of competency-oriented ethics teaching in the health professions. At the same time, curricula for academic and professional education are currently being realigned, putting an emphasis on the acquisition of (ethical) competencies. Teaching will be more and more oriented towards verifiable competence-based learning objectives.

The working group "ethik learning" of the Academy of Ethics in Medicine (AEM) is currently dedicated to competency-oriented ethics teaching and learning in the health professions. It aims to bring together teachers from scientific and clinical institutions in Germany, Austria and Switzerland. As part of the *KOMETH-Learn* project, the group aims at enabling and encouraging academic and professional teachers to develop competency-oriented teaching formats and to implement innovative didactic approaches. The goals will be achieved by developing and providing: a) a collection of competency-oriented teaching concepts and methods in the form of a digitally available "Ethics teaching toolbox" including a repository of specific case vignettes, b) a text- and workbook for ethics teaching and c) a training concept (teach-the-teacher). Furthermore, the project will intensify the group"s national and international networking activities to allow for knowledge-transfer across different areas and disciplines.

In this presentation, we will present the work of the "ethik learning" group. Furthermore, we will reflect on the potential as well as on challenges of competency-oriented ethics teaching in the health professions and disciplines at a conceptual, organizational and practical level as a way to translate ethics into practice.

2.3.3

Kris Dierickx, KU Leuven, Centre for biomedical ethics and law, Leuven, Belgium
Shila Abdi, KU Leuven, Centre for biomedical ethics and law, Leuven, Belgium
Ben Nemery, KU Leuven, Centre for biomedical ethics and law, Leuven, Belgium

Do we achieve anything by teaching research ethics to starting PhD students?

Objective
Education of young researchers has been proposed to promote research integrity. However, the effectiveness of research integrity education on PhD students is unknown. Therefore, we evaluate the immediate impact, as well as its retention over three months in a large sample of PhD students from biomedical sciences, natural sciences, as well as social sciences/humanities.

Methods
In a longitudinal design, we surveyed over 1000 starting PhD students from various disciplines regarding knowledge, attitude, and behaviour before, immediately after and 3 months after a compulsory 3-hour course given by a panel of experts. We compared the improvements of the PhD students with a control group who did not follow the research integrity course.

Results
Significant increases in knowledge scores at the post-test compared to pre-test were observed in both the intervention and control groups, but the increase was significantly higher in the intervention group than in the control group. Significant increases were also observed for attitude scores in both groups, at the post-test and at the follow-up test, with only the post-test increase being significantly higher in the intervention group than in the control group. The analysis of behaviour items on a 4-point Likert scale showed a significant but small improvement towards better behaviour in the intervention group compared to a significant decrease in the control group. However, when we analysed behaviour through yes/no items, there was a significant increase in both groups, unlike when using the Likert scale, the changes did not differ. The majority of participants (93%) reported having had conversations about research integrity, mainly with fellow PhD students. The majority of the participants (79 %) also indicated that they had applied/used the information received during the course, mostly regarding authorship (24%), data management (22%) and publication (18%).

Conclusion
A positive outcome of our study was the significant though modest improvement of PhD students" scores on knowledge and attitude, and the prolonged impact for some behavioural items. In addition, most participants indicated that the lecture had led to discussing research integrity issues and even applying the content of the course in their daily research practice.

2.3.4

Andrea Radvanszky, University of Zurich, Institute of Biomedical Ethics and History of Medicine (IBME), Zurich, Switzerland

Translation of qualitative interviews. Implementing patient narratives in medical education. Examples from DIPEx Switzerland.

Background

The demand for patient-centeredness in research and healthcare has a long tradition. Qualitative research has been an important methododological approach to better understand the patients' perspectives as it allows to gain a deep understanding of the affected narratives. Nevertheless, the perspective of patients and their caregivers often remains subordinated to the medical-oriented view in healthcare. This is partly because the translation of qualitative data into medical practice is challenging. Only few of methodological approaches exist that distinctively translate qualitative research to medical practice.

Method/Aim

The Swiss DIPEx approach ("Database of Individual Patient Experience") is currently being set up and follows a systematic qualitative approach to reconstruct patient experiences in different illness contexts. Based on patient narratives DIPEx serves as a foundation to promote patient-centeredness in the healthcare system. It includes an extensive pool of qualitative interviews (ranging from semi-structured to narrative) with patients and caregivers. The interviews are analyzed on basis of sophisticated qualitative methods and passages are publicly accessible in text, audio and video clips on the online-platform www.dipex.ch. As first-hand experiences they provide orientation for the patients and caregivers regarding their individual health issue. They help to reflect one's own experience, to make informed decisions and to find solutions for challenges, like developing health literacy and adaptation processes to the illness. DIPEx Switzerland aims to use these interviews for both medical training and continuing medical education to translate the knowledge obtained in the interviews to medical practice.

Approach

The interviews offer a direct source to design exercises and lectures close to reality, to raise awareness of patient-relevant topics, to train communication skills in clinical-ethical practice and to foster a reflective attitude in the medical staff. Presenting videos on exemplary topics like "diagnostic interview" and "informing the patient", I will show how patient interviews can be utilized and didactically prepared in the curricular structure of medical studies. I will address both, methodological and practical considerations such as: What is the difference between a simulated doctor-patient conversation (tutorial video) and a doctor-patient conversation remembered and narrated by the patient (patient interview)? What do I do if the perspective on the narrated actors and the social settings remains fragmentary in the patient interview? How can both videos be productively combined? Based on which criteria do I select an interview sequence? Should we be focusing on the individual case or on cross-case categories? How do we balance the results of the qualitative study with the goal of providing educational content?

Discussion

In a short discussion section, I will discuss the benefits of the videos compared to written text, like case examples and to other forms used in the students curricula. I will address the institutional, professional, and organizational requirements for a successful translation of qualitative research results into medical education.

2.4.1

Anna Maas, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany
Sabine Salloch, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany

Paediatric informed consent procedures – A potential clinical application for Large Language Models?

Informed consent displays both an ethical concept and a legal requirement for medical interventions. In paediatrics, some practical challenges of informed consent procedures originate from the adaption of a concept designed for physicians and adult patients to a three-part therapeutic relationship including parents, children and health care professionals. Frequently, the concrete implementation of paediatric informed consent procedures in clinical practice deviates from its theoretical ideal.

Large Language Models (LLM) as powerful technological tools with a wide range of potential applications increasingly find their way into healthcare, including some applications that have been suggested and implemented at very early stages in the paediatric context. The use of LLM in clinical practice poses a number of ethical challenges, requiring special consideration of the chances as well as the risks for certain patient groups such as children.

The aim of this project is to assess the ethics of healthcare practice in view of technologies using generative artificial intelligence. More concretely, we explore the hypothetical chances and risks of LLM use in paediatric informed consent procedures.

To this end, we begin with a literature review gathering information both about LLM use in paediatric pilot studies and from empirical as well as conceptual ethical studies on the application of LLM in informed consent procedures. We then consult a concrete paediatric decision-making framework including six recommendations to analyze ethical chances and risks for the use of LLM in paediatric informed consent procedures.

There are steps in this project where a gap between ethical theory and practice becomes apparent: Firstly, a theory-practice gap can be located between the theoretical conception and an ethically favourable practice of informed consent in paediatrics. Secondly, the ethical principles that have been theoretically formulated for artificial intelligence technologies need to be translated into practical recommendations to consider the use of LLM in paediatric clinical practice.

Bridging these gaps between ethical theory and practice requires careful consideration of the conceptual, methodological and practical challenges of translational ethics. By taking these challenges into account, this ethical analysis about the potential use of LLM in paediatric informed consent procedures aims to be an example of translating ethics into healthcare practice.

2.4.2

Eike Buhr, University of Oldenburg, Oldenburg, Germany
Mark Schweda, University of Oldenburg, Oldenburg, Germany

Use of AI in psychiatry - ethical challenges in theory and practice

AI-based expert systems are increasingly finding their way into psychiatric research and practice. They are intended to enable more precise prediction, early detection and diagnosis and thus also more targeted treatment of psychiatric disorders. A fundamental problem with AI is that increased precision comes at the expense of explainability. This so-called opacity is particularly challenging for psychiatry, as the understanding of the pathomechanistic concept of distinct mental disorders differs widely among different disorders, such as Alzheimer's dementia and depressive disorders. Accordingly, the possibility of validating opaque AI results as real disease entities also differs. The use of AI in psychiatry is therefore associated with theoretical questions that bear important ethical consequences. Since psychiatry is a sensitive field traditionally based on dialog and a trusting doctor-patient interaction, these questions appear particularly urgent.

We therefore examine the ethical implications of the use of artificial intelligence systems that either arise from assumptions of psychiatric theory or are rooted in the specific nature of psychiatric practice. In order to translate such ethical considerations into practice, it is necessary to include relevant stakeholders. In addition to theoretical ethical considerations, we therefore conducted interviews with ethicists from the field of AI and psychiatry (n=5) and with clinical researchers and physicians from the fields of dementia (n=5) and depression (n=5). We combine the results of the theoretical considerations with the results of the interviews and present the ethical challenges posed by the use of AI in psychiatry in the form of concerns and expressed needs. On this basis, we formulate criteria regarding both theoretical aspects of psychiatry and ethical issues of practical care, the self-image of physicians, as well as the doctor-patient relationship. For example, we discuss the theoretical implications that the use of AI has for our understanding of psychiatry, such as whether the use of AI implies a certain concept of mental disorders and what this means for the allocation of psychiatric resources. Furthermore, we analyze questions of attribution of responsibility, the basis of the trusting doctor-patient relationship in the context of AI, challenges regarding the opacity of AI-systems, the peril of over-reliance and deskilling of psychiatrists, possible implications for future medical training, as well as the role of understanding of meaning in the context of psychiatric diagnosis and therapy.

Our approach shows that integrating relevant stakeholders in the process of ethical judgement and combining different perspectives is of particular value in the context of new phenomena like the use of AI in psychiatry. In this way, our approach enables the formulation of ethical recommendations with direct reference to practical needs. This makes it possible to explicate theoretical assumptions of the use of artificial intelligence systems in psychiatry, to anticipate ethical challenges and thus to create the basis for translating ethical considerations into practice so that clinicians are aware of ethical challenges, can uphold appropriate principles and can maintain a high standard of patient care in both medical and ethical terms.

2.4.3

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Marie-Christine Fritzsche, Technical University of Munich, Department of Clinical Medicine, Institute of History and Ethics in Medicine, Munich, Germany and Technical University of Munich, Department of Economics and Policy, School of Management, Munich, Germany
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Embedded Ethics in Practice: A Toolbox for Integrating the Analysis of Ethical and Social Issues into Healthcare AI Research

Integrating artificial intelligence (AI) into critical domains such as healthcare holds immense promise. Nevertheless, significant challenges must be addressed to avoid harm, promote the well-being of individuals and societies, and ensure ethically sound and socially just technology development. Innovative approaches like Embedded Ethics, which refers to integrating ethics and social science into technology development based on interdisciplinary collaboration, are emerging to address issues of bias, transparency, misrepresentation, and more. This paper aims to further develop this approach to enable future projects to effectively deploy it. Based on the practical experience of using ethics and social science methodology in interdisciplinary AI-related healthcare consortia, this paper presents a set of methods that have proven helpful for embedding ethical and social science analysis and inquiry. They include (1) stakeholder analyses, (2) literature reviews, (3) ethnographic approaches, (4) peer-to-peer interviews, (5) focus groups, (6) interviews with affected groups and external stakeholders, (7) bias analyses, (8) workshops, and (9) interdisciplinary results dissemination. We believe that applying Embedded Ethics offers a pathway to stimulate reflexivity, proactively anticipate social and ethical concerns, and foster interdisciplinary inquiry into such concerns at every stage of technology development. This approach can help shape responsible, inclusive, and ethically aware technology innovation in healthcare and beyond.

2.4.4

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Leveraging AI-Based Chatbots to Enhance Patient Consent in Healthcare: A Digital Ethical Perspective

Digital technologies, particularly artificial intelligence (AI), are increasingly shaping the landscape of healthcare, offering novel solutions to complex ethical dilemmas. Within this context, we explore the role of AI-based chatbots in facilitating patient consent during diagnostic procedures and therapeutic interventions. Drawing upon principles of medical ethics and digital innovation, we aim to analyze the potential of AI-chatbots in translating ethical considerations into tangible practices within healthcare settings.

The traditional process of obtaining patient consent has often been fraught with challenges, including comprehension barriers, time constraints, and variations in communication styles of the healthcare provider. In response, AI-based chatbots present a promising avenue for streamlining the consent process while ensuring that patients are adequately informed and empowered to make autonomous decisions regarding their healthcare. AI-based chatbots can aid physicians in taking patient"s medical history and can greatly improve patient education by simplifying medical information and providing personalized recommendations. It also helps with cross-cultural communication in healthcare and can assist in reducing physician burnout by handling routine tasks. However, ethical considerations must be taken into account when integrating AI technologies into healthcare practices.

Through an analytical lens, we plan to examine the mechanisms through which AI chatbots can enhance patient consent. These mechanisms include personalized communication, real-time information dissemination, and interactive dialogue tailored to individual patient preferences and comprehension levels. Moreover, AI chatbots have the capacity to adapt to diverse cultural and linguistic contexts, thereby promoting inclusivity and equity in healthcare decision-making.

Furthermore, we explore the ethical implications associated with the integration of AI chatbots into healthcare consent practices. Key considerations include data privacy, algorithmic transparency, and the preservation of patient autonomy amidst technological mediation. By critically evaluating these ethical dimensions, healthcare practitioners and policymakers can develop robust frameworks that uphold patient rights and foster trust in AI-driven healthcare systems.

In conclusion, the integration of AI-based chatbots holds significant promise for enhancing patient consent processes within healthcare settings. However, successful implementation requires careful consideration of ethical principles, technological safeguards, and ongoing stakeholder engagement. It is important to remember that technology should enhance, rather than replace, the human element in healthcare. Physicians' empathy, emotional understanding, and judgement are invaluable. By embracing the potential of digital technologies while upholding fundamental ethical values, healthcare providers can pave the way for a more informed, transparent, and patient-centered approach to consent in diagnostic and therapeutic contexts.

2.5.1

Christiane Burmeister, University of Tübingen, Institute for Ethics and Medical History, Tübingen, Germany
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Decision-making & diversity: The limits of Standardized Deliberation in healthcare facilities

Clinical ethics support (CES) in patient care is one of the established fields of work that have emerged in recent decades as part of the institutionalisation of medical ethics. The professional requirement to apply standardised procedures of decision-making has led to the development of methods of moral case deliberation: They reflect the professional aspiration to translate ethics into the area of medical practice by adhering to certain rules of discourse. Authors of such procedures claim to directly or indirecty include all stakeholders involved, often emphasizing the discourse-ethical meta-norm of multiperspectivity within a fruitful deliberation process. Hence, at first sight, the advantaguous aspect of multiperspectivity seems to correlate positively with the diversity of the deliberative group, for it increases the number of perspectives on the respective problem. This view, we argue, might fall short of the everyday ethical challenges within healthcare facilities. As we seek to show, a high range of diversity does not simply improve the deliberation process by adding perspectives and positions, but might put into question *the procedure itself*.

In order to substantiate this claim, we want to point out that cultural, ethnic or religious diversity affects not only the variety of value perspectives but also the interpretation of terms and concepts as linguistic utterances as well as the rules of expressing, explaining and discussing them. This appears all the more important as many ethical challenges especially in longterm healthcare facilities are less dire predicaments in a matter of life and death but rather linked with difficult-to-grasp questions concerning the value and quality of living, suffering and dying.
On this ground we want to discuss problems that arise from applying standardized models of ethical decision-making if they do not consider the aspect of diversity:

1. the problem of misunderstanding terms and concepts, even if they are placed as instructed by the instrument
2. the deeper problem of misconceived placing of terms, ("thick") concepts and arguments
3. the diversity of "rules of balancing", e.g when it comes to balancing rights
4. the diverse attitudes towards arguments and how to ""make a point".

By discussing these problems, we want to stress that standardized procedures of ethical decision-making are likely to benefit the exact communication culture they have been developed in and are prone to communicative injustice in highly diverse groups. Last but not least we want to sketch the resulting research and practice desiderata for CES in healthcare facilities to meet these challenges.

2.5.2

K. S. Sophie Gothan, Martin Luther University Halle-Wittenberg, Institute of History and Ethics of Medicine, Halle (Saale), Germany
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Decision-Making in Gender Affirming Medical Care/Surgery (GAMC/GAS): A Systematic Review and Ethical Evaluation of Guideline Recommendations

Background
Gender Affirming Medical Care/Surgery (GAMC/GAS) is increasingly recognized as an essential component of healthcare, yet it presents numerous clinical and ethical challenges. The decision-making process involved in providing medical care to trans* individuals necessitates navigating a delicate balance of various interests and values, including the right to self-determination, benefit and harm as well as related concerns among the treatment team about making incorrect decisions leading to potential later regret. To address these complex issues, various organizations have developed guidelines focusing on ethically relevant aspects.

Research objectives:
1. to evaluate the quality of existing guidelines.
2. to describe the content of guidelines concerning ethical aspects with a particular focus on recommendations related to decision-making about GAMC/GAS.
3. to provide an ethical evaluation of recommendations on decision making about GAMC/GAS.

Methods
We conducted a systematic review of recommendations concerning GAMC/GAS. Given the uncertainty surrounding terminology and definitions in scientific publications, we clarified the terminology (e.g., GAMC, trans*) used in our study before addressing the research question. Methodologically, we followed the PRISMA guideline and conducted a systematic literature search and review in PubMed up until March 2024. In addition, national guidelines pointed out by experts in the field were included. The quality assessment of internationally published guidelines was performed by means of AGREE II criteria. Content analyses regarding agreements and divergences concerning recommendations on decision-making were conducted in the included guidelines. Ethical analysis was performed using a mid-level principlist approach, framed within the four principles of Autonomy, Non-Maleficence, Beneficence, and Justice according to T. L. Beauchamp and J. F. Childress.

Result
The initial search yielded 247 results, with 138 remaining after the deduplication process.
Four publications were preliminary identified as fitting with the definition and meeting the inclusion criteria of guideline on GAMC/GAS.
The quality analysis of these included guidelines revealed scores ranging from 59 to 101 points according to AGREE II.
Preliminary analysis of the content of guidelines revealed that not all guidelines addressed issues of decision-making content. Guidelines providing recommendations on decision making showed considerable differences regarding the involvement of treatment seekers. In addition, guidelines differed regarding procedural prerequisites (such as fixed timeframes) before individuals could undergo GAMC/GAS. Preliminary ethical analysis indicates differing concepts of autonomy and possible limitations underlying the different guidelines and recommendations

Discussion
Quality assessment and ethical analyses of decision-making recommendations in GAMC/GAS-Guidelines can serve as starting point for further informing good practice. We will present details of our then finalized analyses and discuss options for future guideline development on this topic.

2.5.3

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Queering healthcare with digital technologies: How the digital transformation can contribute to diversity- and queer-sensitive healthcare

Self-tracking-technologies serve as a good example for how digital technologies can not only change individual health habits but also put to test the healthcare system as a whole by providing new potentials and challenges. Thus, self-tracking – "[t]he permanent gathering and evaluation of self-related data in one's daily life [...] by using digital technologies" (Heyen 2020, 124) – is understood to have an ambivalent effect in healthcare. While proponents emphasize the potential for individualized healthcare, higher cost-efficiency, and new research data, opponents stress the risk that these technologies will reinforce already existing inequalities and injustices, particularly gender-related inequalities. Thus, feminist analyses of self-tracking-technologies show that these technologies are loaded with gender-related normative assumptions and consider different genders only inappropriately regarding access, design, data base, and implementation. However, a specific queer-feminist perspective on the potentials and pitfalls of the implementation and use of self-tracking-technologies in medicine and healthcare as well as their consequences for just healthcare is largely missing. Furthermore, the opportunity to use queer-sensitive technologies to contribute and, in this way, translate diversity- and queer-sensitivity as a fundamental claim of justice in healthcare is often not considered.

Against this backdrop, the paper aims at analyzing three exemplary cases of self-tracking-technologies in healthcare from a queer-feminist perspective to identify potentials and pitfalls how these technologies can serve as a starting point to shape a queerer healthcare system and how the digitalization offers opportunities to translate diversity-sensitivity in healthcare.

To this end, we proceed as follows: First, we provide a short introduction to self-tracking in medicine and healthcare and show how self-tracking-technologies run risk to reinforce and reproduce gender-related inequalities and injustices regarding access, target, design, database and use/implementation. Then, we introduce a queer-feminist perspective as a methodology examining structural discrimination and marginalization in bioethical research, which we go on to apply in the analyses of three exemplary self-tracking-applications from the areas *nutrition/fitness, reproductive health,* and *mental health*. The analysis of the apps MyFitnessPal, Ava bracelet, and deprexis shows that a binary gender distinction remains a dominant category in self-tracking-systems and that such technologies often fail to acknowledge LGBTQI*(+) people and their needs, thereby reproducing also structural health injustices. We discuss the results of our analysis against the backdrop of already existing queer-sensitive technologies in healthcare. This allows us to identify an equal access, a subversive design, an inclusive data base, and a diversity-sensitive and discriminatory-critical definition of purposes as well as the possibilities of an individualized usage as criteria for a more queer-sensitive development of self-tracking applications.

In a last step, we evaluate to what extent self-tracking-technologies that meet these criteria can contribute to a more queer- and diversity-sensitive healthcare system as a whole. In this course, it becomes apparent that even though such technologies are no panacea, they can nevertheless be an important starting point to shape a queerer healthcare system and, in this way, to translate justice into healthcare. In this way, we can show that if we succeed to shape the digital transformation of healthcare, its disruptive effect offers a unique opportunity to translate ethics into practice.

Reference:

Heyen, Nils B. 2020. From self-tracking to self-expertise: The production of self-related knowledge by doing personal science. *Public Understanding of Science* 29(2):124–138. https://doi.org/10.1177/0963662519888757.

2.5.4

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What kind of ties are genetic ties and why does it matter?

Many people conceived with donor gametes – or otherwise raised separately from their close genetic relatives – want to know *that* they have close genetic ties outside of their immediate family and to know *who* these relatives are. Qualitative research with donor-conceived people testifies to their interest in knowledge of their genetic origins. While secrecy around gamete donation was long encouraged, many countries have banned or are moving towards banning anonymous donation and allowing donor-conceived people to access information about donors. Recent philosophical arguments support this move on the grounds that we have a significant interest in knowing our genetic origins. While this is sometimes formulated in terms of rights, such as a "right to know" the identity of one"s gamete donor(s), I will, in line with others in the literature, more cautiously refer here to significant interests which can, under certain conditions, ground moral claims. But what can these moral claims be, and against whom are they held? Intuitively – and overwhelmingly in the ethics and social science literature – they are claims to know the identity of their genetic parents. However just knowing the identity of one or two individuals is unlikely to give them the answers they seek. Indeed, many donor conceived people express an interest to know about and relate to their genetic siblings or other relatives.

In my talk, I will explore the interest to know of one"s close genetic ties and the implications that it may have for what others ought to do. Should gamete donors let themselves be known by the people conceived with their gametes – and how much knowledge is needed? Do they, for example, need to relate to them in specific ways? While reflection on the significance and risks of parent/child genetic ties outside of the family has not historically been encouraged in the context of IVF, the consideration of non-parental ties has been even scarcer. How should people relate to close genetic relatives they didn"t know they had, such as genetic siblings or grandchildren or nieces and nephews or others? Do donor conceived people also have a claim against close genetic relatives other than the donors themselves – and if so, what claims do they have? These are all important questions that have not typically been discussed with prospective parents upon uptake of IVF treatment with donated gametes or embryos. They are also often not foreseen nor considered when individuals decide to take commercial home DNA tests that reveal unexpected genetic ties. These are the questions that I will explore in my talk.

2.6.1

Ruth Horn, University of Augsburg, Institute of Ethics and History of Health in Society, Augsburg, Germany
Tamar Nov-Klaiman, University of Augsburg, Institute of Ethics and History of Health in Society, Augsburg, Germany
Hilary Bowman-Smart, University of South Australia, Adelaide, Australia

Negotiating severity behind the scenes: prenatal testing in Germany

Fetal-related severity is a key concept in policy and legislation relating to access to both reproductive technologies and selective abortions in many countries around the world, but not in Germany. This study sheds light on how "severity" in the context of prenatal testing is understood and negotiated within the particular socio-cultural and legal context of Germany, where "severity" relating to fetal clinical findings neither counts as a justification to implement population prenatal screening programs, nor as a legal ground to terminate pregnancy.

This study explores the views of women who undergo prenatal testing, as well as of professionals who encounter them, through semi-structured interviews. It showcases how they frame severity, and questions whether the existing legal and regulatory framework relating to prenatal testing and termination of pregnancy addresses their concerns and needs. The interviews (n=27) reveal that despite it being legally outside the explicit reasons for testing and termination of pregnancy, both women and professionals negotiate severity behind the scenes. Their interpretation of severity is highly context-dependent and relies on clinical, social, and familial facets. Their perceptions of severity guide them in their handling of and decision-making around pregnancy management. Acknowledging the personal nature of severity assessment and providing professional or legal guidance which explicitly mentions fetal anomaly as a legitimate factor in pregnancy management could provide healthcare professionals and patients with the room needed to manage the pregnancy favourably.

2.6.2

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Creating ethics guideline for cancer care during pregnancy – work in progress

Question

There are no formal ethics guidelines for clinicians caring for pregnant cancer patients. A theoretically-grounded framework to support ethical and patient-centred care of these patients together with ethics checklist for clinicians has been proposed. How can existing medical ethics guidance be further translated to professional ethics guideline for clinicians attending to the needs of pregnant carcer patients?

Methods

The earlier framework development for ethical and patient-centred care of pregnant cancer patients was based on ethical models identified in medical ethics literature—namely principle-based approaches (by Beauchamp and Childress and the European principles in bioethics and biolaw) and relational, patient-focused approaches (relational ethics, ethics of care and medical maternalism)—informed by a systematic review of ethics content in clinical practice guidelines. Systematic review was conducted adhering to PRISMA statement requirements and only included recommendations for cancer treatment and care during pregnancy endorsed by professional societies representing oncology field. Further ethics guideline development requires direct and active input from clinicians and patients affected by cancer during pregnancy diagnosis.

Results

In a systematic literature review, 25 out 32 clinical practice guidelines published between 2002 and 2021 made references to medical ethics concepts, when offering clinical management guidance for clinicians. Four medical ethics themes were identified: respect for patient's autonomy (recognising its relational aspects), balanced approach to maternal and foetal beneficence (with tendency to prioritise maternal health), protection of the vulnerable (perceived broadly, not limited to foetal protection) and justice in resource allocation. Subsequently, five foundational discussion themes, summarising the key ethical considerations that should be taken into account by healthcare professionals while discussing treatment and care options with pregnant cancer patients, were identified: recognising relational context of individual patient's autonomy and supporting it through caring, patient-focused approach; balancing maternal and foetal beneficence supported by caring, patient-focused and maternalistic approach to patient care; balancing maternalistic and relational approach with evidence-based, personalised patient care; considering protection of the vulnerable in a light of responsibilities towards the unborn child and underrepresented stakeholders, including pregnant patients themselves; ensuring reasonable and just resource allocation to avoid giving pregnant cancer patients false hopes. This was further developed into a comprehensive ethics checklist consisting of 22 directive statements that can be used during clinical appointments and highlights the need for a holistic view to patient treatment, care and counselling while providing ethical, patient-centric care. Patient engagement and clinical feedback sessions are currently being planned to obtain further input from stakeholder groups affected by cancer during pregnancy diagnosis.

Conclusions

Theoretical framework transformation into an ethics checklist for healthcare professionals, which helps to anticipate and address ethical concerns that may arise when attending to pregnant cancer patients was a significant step towards translating medical ethics research into clinical practice. One of major limitations of current proposal is that it is limited to the input from a small research team consisting of two clinicians and two bioethicists. Therefore, further studies exploring clinicians' attitudes towards cancer treatment during pregnancy, feedback on using ethics checklist in their practice and patient experiences when diagnosed with cancer while pregnant as well as wider stakeholder engagement are needed to inform the development of practical, inclusive and representative ethics guideline for healthcare professionals.

2.6.3

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Mentally ill Women with a Desire to have Children: How Translational Ethics can help to develop Instruments for Preconception Counselling

Background
For a long time, the topic of mentally ill women's desire to have children was dominated in research by questions about successful pregnancy prevention and the risks to the "child's well-being". Since the early 1990s there has been an increasingly important line of research within the field of gynecopsychiatry that deals with the subjective meaning of motherhood from the perspective of affected women. This line of research expands the risk-oriented focus and considers the resource-oriented aspects of motherhood. With a view to this line of research, it is important to take a closer look at the personal perspective of women with a mental illness and the requirements for adequate treatment, care, and advice for this patient group. Moreover, by focusing on their individual concepts of life and motherhood, fundamental social and ethical aspects of the mother's and child's well-being become crucial aspects of preconception counselling.

Question / Aim
Decision making in psychiatry is influenced by personal attitudes and professional cultures. Regardless of this, when counselling a mentally ill woman, the focus should always be on the woman's well-being and the well-being of a future child. Therefore, a model for preconception counselling for women with mental illnesses was developed, in order to provide specialists with guidelines for counselling and supporting these women. The project is thus an example of translating ethics through guidance.

Methods
In order to examine the needs of women as a basis for creating the instrument of integrated psychiatric-psychotherapeutic preconception counselling, 21 women of childbearing age with a mental illness (including depression, bipolar disorder, and schizophrenia) and a wish for a child were asked about their attitudes and perspectives on their desire to have children. The perspective of the treating professionals was examined with additional four individual interviews and with the help of focus group discussions. The results of both studies were incorporated into the development of the instrument alongside the current psychiatric, historical, legal, and ethical knowledge from the specialist literature.

Results
Recommendations for specialists for preconception counselling of women with mental illness and a brochure for this patient group were developed. The documents can be found on: www.dialog-ethik.ch/praekonzeptionelle-beratung. Both documents have been recognized by the Swiss Society for Psychiatry and Psychotherapy. The core of the recommendations is the "Integrative Preconceptional Counseling Tool" for mentally ill women of childbearing age ("Integratives Präkonzeptionelles Beratungstool"). The instrument supports specialists in clarifying a possible desire to have children by a mentally ill woman. Moreover, it helps specialists to determine and assess the individual need for support of a woman with a mental illness, if the desire to have children is present. The special feature of the model is to integrate ethical aspects of a woman's life plan into psychiatric counselling with the aim of empowering women based on Martha Nussbaum's capability approach. Thus, this model is an example of how translational ethics can be put into action.

Conclusions
Translational ethics can help to integrate fundamental ethical principles into guidelines, counselling, and decision making in healthcare, such as preconception counselling for women with mental illness. With the implementation of the recommendations for specialists to use the "Integrative Preconceptional Counseling Tool", psychiatrists and other specialists have an approach for counselling of patients that takes into account important aspects of the life plan and fundamental values of a vulnerable patient group such as women with mental illness.

2.6.4

Marcel Zuijderland, AmsterdamUMC/lokatie VUmc, Ethics, Law & Humanities, Amsterdam, Netherlands

Between Existence and Essence: The 'Liminal Being' and 'Sublime Child' in Abortion Ethics

My research delves into the ethics of abortion, traversing its historical evolution and engaging with the philosophical discourse on the moral status of unborn life. Historical and anthropological analyses indicate that abortion, particularly before quickening, has always been morally sensitive yet enjoyed a level of acceptance across various ages and cultures. However, societal changes along with scientific and technological advancements since the 1960s and 1970s have led to a polarized ontological conceptualization of unborn life, depicting it as either a negligible cluster of cells or a fully fledged person. This dichotomy fails to encapsulate the nuanced experiences of pregnant women contemplating abortion, who frequently find themselves oscillating between these extremes.

In this study, I conduct a philosophical examination of the moral status of actual persons and assess how these considerations extend to unborn life, informed by meta-ethical theories. This exploration culminates in the observation that there lacks a compelling philosophical justification for categorically viewing unborn life solely as a person or merely as an inconsequential cluster of cells. Philosophically, unborn life appears to fluctuate between being 'somebody' and 'nobody', thus rendering it most accurately characterized as a 'liminal being'. It inherently embodies both 'somebody' and 'nobody' aspects without a definitive resolution, allowing the observer's focus to dictate which aspect is revealed.

This liminality suggests though that reconciling with the termination of pregnancy is only deemed acceptable when the moral lens is focused on the 'nobody-part' of unborn life. Concentrating on the 'somebody-part' would inevitably lead to viewing termination as the act of killing a person. To navigate this ethical impasse, I propose the concept of the 'sublime child', which encapsulates the immaterial and subliminal nature of unborn life, situated within the realms of the 'collective unconscious'. This allows unborn life to be perceived as 'somebody' without necessarily invoking the tragedy of death and loss upon deciding to terminate the pregnancy. Terminating can be seen as returning this child back to the reproductive potential of the woman. At its essence, the constructs of 'liminal being' and 'sublime child' pioneer a novel perspective that redirects the abortion debate from a rights-based contention to a dialogue centered on mutual recognition and ethical connectivity. This innovative approach introduces a new dimension to the debate, surpassing the traditional pro-choice and pro-life dichotomy. This study emphasizes the importance of integrating historical context and philosophical depth in addressing the ethics of abortion. It advocates for a nuanced understanding of abortion's moral complexities, crucial for devising counseling ethical guidelines that respect both individual autonomy and respect for unborn life. By fostering continuous ethical dialogue, this research aims to contribute to a richer comprehension of abortion within contemporary bioethics.

3.2.1

Tomasz Krawczyk, Jagiellonian University Medical College, Department of Philosophy and Bioethics, Krakow, Poland

Meaningful Inclusion? Influence of Research Institutions on Epistemic Injustice within Patient and Public Involvement

Meaningful inclusion requires not only physical, but also intellectual presence of those to be included. The Patient and Public Involvement (PPI) entails encounters of different worldviews, thus requires changes in shared epistemic resources, such as concepts, meanings and interpretations. However, the changes should occur not only in the epistemic resources of people to be included, but also in those of researchers and the collective epistemic resources of academia. While PPI is a widely accepted practice within the healthcare in the Global North, its various aspects are still debated, among them the epistemic ones. There is a growing literature on epistemic (in)justice within the PPI context. However, the main focus is set on involved individuals facing testimonial and hermeneutical injustice, and the process of involvement. There is a gap concerning structural epistemic injustice in PPI (hermeneutical and contributory injustice) and analysis of research institutions as collective epistemic agents. The issue of how PPI practice influences and is influenced by research institutions is underdeveloped, in particular when it comes to the epistemic features. Therefore, the question remains of how the research institutions contribute to both fostering epistemic justice and perpetuating epistemic injustice within the PPI practice.

I will discuss the epistemic injustice in the context of PPI, focusing on research institutions as collective epistemic agents, prone to epistemic vices (Dotson, 2014; Fricker, 2009; 2021). Then, I will apply the institutional order-of-change frames (Bartunek, Moch, 1987; Walsh, 2005) into the PPI context. Basing on these conceptualisations and existing reviews of PPI research I will outline possible directions of future analysis of research institutions engaged in the PPI practice. I will argue that not only involved participants and individual research team members, but also research institutions should adapt to be good partners in the involvement process. Thus, the focus on epistemic aspects of research institutions is necessary to provide successful outcomes of the PPI practice and, more fundamentally, to create epistemic conditions for meaningful encounters among people who share different worldviews.

3.2.2

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Empowering patient voices: Shaping ethical digital health research together through a collaborative discourse at a stakeholder-conference.

Background
The digitalisation of healthcare and research is driving a paradigm shift in the German healthcare system. In this evolving landscape, Patient Organisations (POs) and Self-Help Organisations (SHOs) play a pivotal role by independently organising medical data documentation in registers, facilitating research and reflecting a step towards patient empowerment within the digital framework. However, despite calls from the German government and patient studies for more active patient participation in digital health research, the specific modalities of this involvement remain to be defined. In addition to this transition, new legislations in Germany aim to integrate data from electronic patient records with existing registries for both public and private research, a process further challenged by the requirements of aligning to the European Health Data Space. This context underscores the complexity of harmonising healthcare digitalisation with cross-border data standards and privacy considerations.
The research project PANDORA "Patient-centred digitalisation: An ethical analysis of the role of patient and self-help organisations as actors in the context of digitalisation in health-related research and care" is hosting a stakeholder conference with German POs/SHOs in June 2024 to facilitate the preparation of a position paper.
The aim of the stakeholder conference is to amplify the patients" voices in the further development of digital health research. Specifically, the following should be determined: How do POs/SHOs perceive the ethical challenges and requirements in the implementation of the secondary data use, broad consent, and active co-design of digital health research, particularly concerning patient autonomy, data privacy, and equitable access and what further ethical considerations could they make?

Methods
A position paper is the result of an innovative, interactive discourse process before and during the conference. Before the conference, non-binding statements will be collected from the invited POs/SHOs on the following key topics: Data collection and secondary data use, broad consent, active co-design of (digital) health research, and other concerns raised by the organisations. These statements are visualised using the "concept mapping" method and problem areas are analysed with a content analysis with MAXQDA. The analysed points of disagreement from the statements will be discussed in working groups at the conference. Finally, a draft position paper on the design of digital health research, which will be jointly supported by the participating organisations, will be prepared. After the conference, there will be a press conference at which the position paper will be presented to political decision-makers in the healthcare system and healthcare policy as well as the public.

Results
The results of the discourse process underline the practical implementation of ethical considerations. The findings unveil varied perspectives on ethical issues in secondary data use, broad consent, and co-design in digital health research, focusing on patient autonomy, data privacy, and equitable access. Further, we will focus on the unique methodical procedure for preparing the position paper.

Conclusion
The interactive process leading to our position paper is an exemplary approach to demonstrate how POs/SHOs can be actively involved in the formulation and implementation of ethical guidelines in digital health research. This not only highlights the need for an inclusive and participatory approach to health research, but also provides a model of how ethical norms and values can be effectively translated into health practice and research.

3.2.3

Silvia Ceruti, University of Insubria, Department of Biotechnology and Life Sciences - Research Center for Clinical Ethics, Varese, Italy

The introduction of Research Ethics Consultation Services in Italy. Theoretical-practical reasons supporting the adoption of a cooperative-collaborative approach to ethical issues raised by clinical research.

Clinical Ethics Consultation Services (CECSs) have yet to become widespread in Italy, but significant efforts have recently been made to ensure their implementation in healthcare facilities in order to address ethical issues raised by clinical practice. In contrast, similar consultation services have not been introduced in the context of clinical research, despite its critical role in the advancement of modern medicine. This exclusion is largely linked to the strictly regulatory approach to clinical research traditionally used in Europe, according to which scientific and ethical requirements for conducting clinical trials are defined by a set of national and international norms and guidelines. As a consequence, the responsibility for evaluating and authorising this research is assigned to local/institutional ethics committees, whose main function is to protect the rights and well-being of research participants. This approach, however, is not always entirely effective, largely due to researchers' lack of knowledge or awareness of the ethical principles and values involved, or the rules and standards of conduct. In other words, there seems to be a shared underlying notion that it is not enough to formulate principles, standards or codes of conduct for these to have a real impact on the behaviour and attitudes of researchers and, consequently, on the protection of research participants and the integrity of the research itself.

To address these challenges, in the United States the functions performed by institutional review boards have been complemented by the activities of Research Ethics Consultations Services (RECSs), which support researchers throughout the research process. Since the effectiveness of RECSs is now well documented, we believe that, to provide concrete support to clinical researchers, the opportunity to introduce such services should be discussed also in Italy, as part of the broader current debate concerning the institutionalisation of CECS.

The aim of this contribution is therefore to propose a model of RECS that, considering the local context, can be implemented in Italy in order to allow the top-down functions performed by ethics committees to be complemented. Accordingly, we argue that, in Italy, RECSs should be developed by adopting a bottom-up cooperative-collaborative approach, which fosters direct dialogue between bioethicists and researchers. In the same way CECSs provide support to address ethical issues raised by clinical practice, these services should provide support to researchers in identifying, analysing and resolving ethical issues raised by clinical research, in particular related to the protection of research participants and compliance with standards of research integrity. More specifically, we present the S.A.T. (Steps, Actors, Topics) Model of RECS, developed using a multidimensional and dynamic cooperative-collaborative approach, according to which ethical issues are considered, continuously updated and addressed, taking into account each step of the research process (Steps), all stakeholders involved (Actors - e.g. researchers, participants, caregivers) and all macro-areas of RECS intervention (Topics - e.g. informed consent process, research integrity, data protection).

Although we maintain that the introduction of the S.A.T. model and, in general, the implementation of RECS may be beneficial in Italy, considering the Italian context and, in particular, the fact that the culture of ethics consultation is still limited, we find it difficult to conclude that such implementation is currently feasible. Consequently, at this preliminary stage, we believe that a sound recommendation would be to include within the CECS, which are gradually becoming widespread, at least a research ethics consultant, who would provide real-time advice to a broad spectrum of stakeholders, with the aim of improving the quality of research which, in turn, can benefit individuals and society.

3.2.4

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Qualitative health research under ethical review. A comparison between review practice and interventions for improvement by applicants and members of medical research ethics committees in Germany

Question
Similar to quantitative clinical studies, most qualitative health studies must be reviewed by a research ethics committee (REC) before they are conducted. Regardless of the study type, RECs must take three perspectives in their ethical assessment of applications: the scientific quality, the ethical justifiability and the legal admissibility of the study. A study is only approved if it is considered ethically appropriate from all three perspectives. However, research has highlighted contradictions between qualitative methodologies and RECs' assessment practices, as these are often guided by the biomedical quantitative paradigm. Our research questions were: What challenges arise in the research-ethical assessment of qualitative health studies by medical RECs in Germany? Which interventions for improvement result from a comparison of the experiences of applicants and members of medical RECs that are useful for both applicants and appraisers?

Methods
This grounded theory study is based on problem-centred interviews with seven researchers having previous experience in applying for ethics approval for qualitative health research projects to medical RECs in Germany, and three focus group discussions with a total of 14 members from 16 different medical RECs in Germany, as some participants were a member of two different medical RECs. The data collection and analysis were carried out circularly according to grounded theory methodology.

Results
The analysis shows that five key themes were discussed: (1) the lack of scientific quality of the application, (2) the lack of expertise in qualitative methods within medical RECs, (3) the potential invasiveness of qualitative research, (4) unpredictable ethically sensitive moments and, (5) privacy and confidentiality. The discussion of these themes reflects two overarching dimensions of challenges: (1) responsibility for ethically legitimate research and (2) justifications for ethical concerns. Although the concrete interventions suggested by participants varied, they reflect that both sides pursue three overarching aims: (1) an increase of expertise in qualitative research on both sides, (2) an improvement of the communication between both sides and (3) an improvement of the framework conditions for both sides.

Conclusions
We conclude that in order to ensure an ethically appropriate review practice of qualitative health research, researchers and medical REC members need to ensure collaboration and collegiality, and that this is already practiced in some places, but not everywhere. Improvement of the review practice can be reached by an increase of expertise in qualitative research on both sides, an improvement of the communication between both sides and an improvement of the framework conditions for both sides.

3.3.1

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Loneliness and solitude experiences of adolescents and young adults during the COVID-19 pandemic: a qualitative systematic review

Public health measures against the Covid-19 pandemic, have caused an increase in loneliness prevalence. This was already considerably high in many countries before the pandemic. Research shows that not only the older population, but also and especially younger adults and adolescents, were greatly affected by the measures in terms of experiencing loneliness. Adolescence and young adulthood are a period of life in which meaningful human relationships are crucial for the building of identity and personality development. Moreover, researchers have drawn attention in the last years to the association of loneliness with both physical and mental health. Pre-COVID-19 pandemic preparedness plans did not take into consideration the effect of restriction measures on the need for social connection, especially for vulnerable groups. From an ethics of care perspective, such needs should be taken into account when designing and implementing public health measures. A systematic review about how the Covid-19 pandemic has affected adolescents and young adults" feelings of loneliness does not exist so far, and constitutes a highly valuable knowledge for informing ethically-sound approaches for future virus-contention measures. This work shows the results of a systematic review aiming at meeting this knowledge gap. Qualitative studies conducted between 2020 and 2024 focussing on the loneliness experiences in adolescents and young adults have been collected through 6 databases (Scopus, PubMed, Web of Science, PsycInfo, CINAHL and Sociological Index) and through Google Scholar. Relevant information has been extracted and synthesised according to best-fit framework analysis, and reporting has been performed following ENTREQ (2012) —Enhancing transparency in reporting the synthesis of qualitative evidence— and PRISMA (2020) statements. The results of this review can shed light on the needs of this population in pandemic-crises, and constitute a first step for further ethical reflection on how to better prepare for future pandemic scenarios based on an ethics of care approach.

3.3.2

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Professional ethos under pressure: what internal tensions did healthcare workers have to face during the COVID-19 pandemic? Results of a qualitative study with detailed insights into ethical and individual challenges

In their everyday work, healthcare workers experience the effects of tensions between professional ethos and work reality, which can lead to moral dilemmas that become particularly apparent in health emergencies. Our aim was to take a closer and more concrete look at the dilemmas faced by healthcare workers in Germany during the COVID-19 pandemic and to understand them in the context of the German healthcare system.

Between April and December 2022, we used focus group discussions and individual interviews with employees from various health care facilities and settings in the German healthcare system as well as interviews with political decision-makers and managers of healthcare facilities. Participants were asked about their personal experiences, challenges, coping strategies, factors supporting or hindering health care workers in coping with challenges, support needs, and recommendations for better support.

Based on the analysis of the data from 78 participants, three main topics were identified. The first topic comprised statements on the extent to which pre-existing problems in the healthcare system have intensified during the COVID-19 pandemic. The second topic covered the moral dilemmas that were described as a result of the tension between professional ethos and structural constraints. The third topic included factors that reinforce or mitigate the effects of moral dilemmas. A key finding of the study is that political or institutional regulations and measures are often adopted without the involvement of healthcare professionals. Such decisions do not do justice to the work processes or the needs of healthcare staff and can jeopardise patient care. Positive interpersonal interactions were described as helpful in overcoming dilemmatic decision-making situations.

The working conditions of healthcare professionals regularly lead to moral dilemmas that come to a head in health emergencies of national or international scope. In order to mitigate or avoid the consequences of unresolved ethical dilemmas due to a general scarcity of resources and individual moral dilemmas potentially resulting in moral distress among healthcare professionals in the future, staff shortages and decision-making processes in the German healthcare system must be urgently addressed, remedied and adapted. Together with healthcare workers, political decision-makers and managers of healthcare facilities must develop new models for working in the healthcare sector that are in line with the professional ethos of healthcare workers.

3.3.3

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Moral Injury Experiences and Perceptions of Self as A Moral Subject of Healthcare Workers Working in and behind the Field in the Earthquakes of February 6, 2023 in Türkiye: Developing Quality Criteria and Solution Suggestions for Moral Resilience

Moral injury is a type of negative affective disturbance experienced by those who have witnessed sudden and severe emotional damage, intense human suffering and cruelty. It can undermine the values, perspectives, attitudes and justifications that underpin the person"s moral integrity.
On February 6, 2023, the earthquakes of magnitudes 7.7 and 7.6 caused significant damage to housing and public infrastructure, affecting both Türkiye and Syria. The disaster resulted in a significant loss of life, with over 50,000 deaths officially reported across 10 provinces in Türkiye. The event raised public health concerns and sparked debates on earthquake preparedness. One important ethical issue is the possibility that healthcare workers, who play a key role in the functioning of health services in the earthquakes, may experience moral injury which can lead to burnout and alienation. For instance, a considerable number of healthcare workers working in the region during and after the earthquakes were reported to quit their jobs.
Our research project aims to gain insight into the moral injury that healthcare workers may have experienced while conducting and/or managing critical treatment and care services during the aforementioned earthquakes. It will be questioned how they cope with the moral difficulties they experience and how these experiences determine their perception and position as moral agents. The secondary aim of the study is to develop basic principles (quality criteria) for the planning and organization of healthcare services in disasters and to develop short-term feasible solutions to the existing problems. These stages aim to contribute to increasing healthcare workers" moral resilience.
The study will include healthcare workers who served in various roles, duties, and positions during the February 6, 2023 earthquakes. It is designed as a descriptive, participatory, cross-sectional and mixed method research and will be carried out in four stages: 1) Determination of the prevalence of moral injury for the specified population; 2) conducting and analyzing semi-structured in-depth interviews with participants with high and low moral injury scores, 3) evaluating the validity of the qualitative data through focus groups, and 4) developing quality criteria and practical solution suggestions in the light of the findings in a Socratic dialogue workshop with the participants.The project has been submitted to TÜBİTAK, Türkiye's national science and technology institution. The two-year research project is the first study that addresses this subject in Türkiye.
In this presentation we will discuss the main framework and the preliminary findings of our project.

3.4.1

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Emerging Technologies and Vulnerabilities in Older Adults without Cognitive Impairments: a Systematic Review of Qualitative Evidence

Background
Aged care has recently undergone major transformations due to an increasingly prominent demographic ageing and the concomitant need to manage the costs of healthcare. New Emerging Technologies (ET) have started to play a central role in the daily management of older adults, also with a view to the so-called Active Ageing. In order for these transformations to effectively promote successful ageing, it is essential to understand the opinions of older adults on the impact that technology can have on their vulnerabilities and ageing process.

Methods
Using the PRISMA procedure, we conducted a systematic review of empirical (qualitative) evidence exploring the relationship between ET and older adults" vulnerabilities as perceived by older adults without cognitive impairments. Five major databases (Pubmed, Embase, Web of Science, CINAHL and Philosopher"s Index) were queried, covering biomedical, philosophical, bioethical, and anthropological literature. 11.631 results were obtained. After duplicates had been eliminated, titles, abstracts, and full texts were screened for relevance. Eventually, 70 articles were included. Data analysis and synthesis followed the preparatory steps of the coding process detailed in the QUAGOL methodology.

Results
ET seem to have an ambivalent effect on the vulnerability of the still cognitively independent elderly population. These devices tame some already existing vulnerabilities, and, at the same time, they worsen already existing – or create new – vulnerabilities. For example, Unconventional Monitoring Techniques (e.g., wearables and environmental sensors) often tame *relational* vulnerability, because they are perceived as a support to maintain independence and remain at home and in one's community. On the other hand, these same devices may negatively affect *moral* vulnerability, threatening older adults" privacy, in the sense of confidentiality, as ET could violate their personal data.

Conclusions
This systematic study, focusing on the perceptions of older adults *without* cognitive impairments, enriches the vast literature on the subject of the everyday management and care of the elderly, by exploring the ethical implications of ET. This research, in particular, is a complementary work to another systematic review of the qualitative evidence, aimed at analyzing the views of elderly people *with* cognitive disorders on the same topic. Although a certain ambivalence in the use of ET is identified by both population groups, it is interesting how the cognitively healthy elderly give more importance to some dimensions of vulnerability, such as the moral and relational dimensions, which, in the case of the cognitively impaired elderly, are not as significant, with regard to the use of ET. Two issues which are emblematic and particularly felt by this population is the respect of privacy and data security and the perceived risk of control and surveillance linked to the use of monitoring technologies.

3.4.2

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Care Across Borders: A Practice Oriented Analysis of Vulnerabilities in Migrant Live-in Home Care for Persons with Dementia in Germany and Israel

In many Western countries, including Israel and Germany, engaging migrant live-in carers in dementia care has become a common practice. This approach creates a unique triad of relationships and potential vulnerabilities among individuals with dementia, their family members, and migrant live-in carers.
In our study, we provide a comparative perspective on the complexities within this triad and explore experts" perceptions and assessments regarding migrant live-in home care arrangements for older persons with dementia in Germany and Israel.
While both countries adopt a familial and somewhat privatized care model, disparities emerge for example in the duration of stay for migrant live-in carers within a family and the extent of involvement of placement agencies, resulting in distinct vulnerabilities. Migrant live-in carers in Germany typically rotate every two to three months and live in shuffle migration. In contrast, the live-in care arrangement in Israel tends to be more stable. In our study, we seek to address the following inquiries:
What are common and specific vulnerabilities for each party involved in the caregiving process? What commonalities and differences exist between the migrant live-in caregiving systems of Israel and Germany?
Addressing the imperative of translating ethics into healthcare practice, we explore the cultural sensitivity, fair treatment, legal frameworks, policy development and the overall ethical approach required for equitable and compassionate care in the migrant care setting.
This study applied a qualitative method using semi-structured interviews with German (n=10) and Israeli (n=14) experts in migrant dementia care, including representatives from placement agencies, legal professionals, social workers, and NGOs. A comparative thematic analysis was conducted to extract key themes.
We identified similarities and differences in expert opinions in Germany and Israel regarding migrant live-in home care for persons with dementia. The analysis revealed common and specific vulnerabilities among individuals with dementia, their families, and migrant caregivers, as well as systemic factors at a meso and macro level impacting all parties in the care triad.
In general, Israeli experts highlighted the complex nature of vulnerability, suggesting that neither party involved in the caregiving dynamic is more vulnerable than the other. Instead, vulnerability may manifest based on specific circumstances affecting each individual.
The German experts, however, directed their attention to the vulnerability of migrant live-in carers, highlighting their exposure to discrimination, excessive working hours, and difficult working conditions coupled with a lack of autonomy.
Our research underscores the complex vulnerabilities in migrant home care for persons with dementia in both countries. It demonstrates that while certain challenges are universal, their manifestations and solutions vary due to each country's different cultural and systemic contexts. The study thus emphasizes the need for tailored policies and practices that address the specific needs of individuals with dementia, their families, and caregivers within this arrangement. The findings underscore the importance of understanding and mitigating vulnerabilities in dementia care through a culturally sensitive and comprehensive approach. By delving into cultural nuances and recognizing the potential vulnerabilities, we highlight the necessity for a comprehensive ethical approach in healthcare practices with the overall aim to contribute valuable and comprehensible insights for migrant healthcare stakeholders and practitioners.

3.4.3

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Qualitative research in support of empowering participation of children in SIRS research

Background
The Systemic Inflammatory Response Syndrome (SIRS) is a rare disease but significant cause of mortality in children. This predetermines the focus of research in the direction of diagnosis and therapy of SIRS, but the accompanying ethical aspects remain understudied. Our report is based on ethical results, founded by Federal Ministry of Health (BMBF), of ERA PerMed project "Tailored immunotherapy for pediatric SIRS patients" (TIPS). TIPS is implemented by an interdisciplinary European consortium with project leader Prof. Dr. Catharina Schütz, University Hospital Dresden, Germany.

Methodology
In this paper we *aim* to focus on the experts" opinions about the empowerment of participation of children. Qualitative research methodology involving semi-structured interviews with 10 experts with different backgrounds. Systematic literature review grounded the interview questionnaire. The interviews" transcripts were subjected to thematic analysis by two independent researchers.

Results
The empowerment of children was considered important and the obtainment of informed consent rather than assent was seen as a common goal. Instruments designed to inform children were supported while tools for assessing children"s maturity were beneficial only in non-emergency situations. The emergency context hindered the obtainment of informed consent for research. Still the experts pointed out that information should be delivered to the children themselves after the emergency was coped with. The decision of custodials alone was not sufficient if children, who were deemed to understand the risks and aims of the study, declined participation, regardless of legislation or age. The current standards for research with children, including research in emergency situations, were found not specific enough and lacking practical guidance.

Discussion
The experts were well aware of the ethical and legal standards concerning the informed consent process. Additionally, the autonomy of children was valued higher than could be expected for an emergency situation. Since SIRS diagnosis presents challenges, these patients are addressed as the rest of the sepsis pediatric patients and no specificity of the informed consent process can be identified.

Conclusion
Although generally proclaimed and widely supported in the recent ethics literature, the empowerment of the participation of children is not well backed up by the existing regulation. The existing tools lack specificity and flexibility. Here comes the role of the qualitative research that can build the necessary base of evidence for the development of practically oriented guidelines. That is especially the case with the rare diseases and special patients" groups, as paediatric SIRS, which fall outside of general frameworks.

3.4.4

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Nursing homes in times of a pandemic: to close or not to close?
Reflections on restriction measures during the COVID-19

The COVID-19 pandemic necessitated the development of guidelines for allocating limited resources, which sparked ethical debates surrounding the inclusion of age and disabilities in the triage process. Many moral questions were raised, for example because there were instances of age-related prioritization and disparities in care access, generating doubts about fairness and equity during resource scarcity. Collecting empirical evidence around these issues, and understanding elderly patients' experiences in such situations are crucial to improve healthcare practices during times of limited resources.

The project "Decision making in times of scarce resources: A mixed-method study" made by research group from Institute for Biomedical Ethics in Basel, Switzerland, aims to generate ethical guidelines for prehospital triage during situations where resources are limited, with a specific focus on the care of older adults. To achieve this, the study pursues several goals, including understanding the experiences of older patients during the COVID-19 pandemic, exploring the perspectives of stakeholders involved in resource management, and investigating ethical dilemmas in prehospital triaging. The research employs both quantitative data collection from older patients and qualitative interviews with decision-makers. By analyzing the data, the project seeks to provide valuable insights into healthcare planning, resource allocation preferences, and ethical challenges faced during public health emergencies. The ultimate outcome will be evidence-based recommendations for effective resource management, with a particular emphasis on providing quality care to vulnerable elderly patients.

During the pandemic, quarantines were imposed in many countries (including Switzerland). Most nursing homes have shut their doors to the public, making them completely closed institutions. Even people under 65 years old in the homes struggled to cope with the quarantine, but it was particularly hard for nursing home residents, especially those with different psychological and mental conditions (dementia, Alzheimer's disease, etc.).

In this paper we would like to address the issue of avoiding or promoting restriction measures in times of pandemics in such social institutions, to analyze the experience of doctors and managers taking such measures, and to propose solutions in case such a situation returns.

3.5.1

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Orchestrating Best Interests Decision-Making: A Qualitative Study of Best Interests Decision-Making in Healthcare in England and Wales

Introduction
In many legal systems, including England and Wales, decisions about the treatment and non-treatment of patients who lack the mental capacity or competence to decide for themselves are governed by the "best interests" standard or test. Whilst the test is therefore familiar in many legal and clinical settings, it remains an open question what the test does and should encompass, how decisions on this basis are and should be made, and who should be involved in making these decisions.
This presentation shares some results from the Wellcome Trust-funded BABEL project (Balancing Best Interests in Healthcare, Ethics and Law). Running from 2018 to 2024, this "empirical bioethics" project explores best interests decision-making in healthcare for and with people across the life course. The project comprises literature reviews and empirical research with a range of people involved in, or subject to, best interests decision-making.

Methods
This presentation presents a theme developed from some of the qualitative research undertaken during the BABEL project. It specifically focuses on findings from interviews and focus groups with healthcare professionals and patients, which explore how best interests decisions are currently made. The study received research ethics approval from the University of Bristol Health Sciences Research Ethics Committee (reference 118590). We conducted 22 interviews (21 individual interviews and one dyadic interview) and three focus groups (comprising 10 participants), leading to a total of 33 participants. We undertook thematic analysis of the transcripts, with themes developed after line-by-line coding. This presentation reports on one of our themes and its five sub-themes.

Results
This presentation reports the theme of orchestrating best interests decision-making, which contains five sub-themes. The first sub-theme captures the "orchestra" of best interests decision-making, in which various people assume different roles and responsibilities. The second sub-theme explores communication as not only a source of disagreement, but also as a means of securing consensus. The third sub-theme reflects how values and emotions drive the determination of best interests. The fourth sub-theme captures diverse but related understandings of "best interests", which emerges as both a pluralistic and a polysemous concept. The final sub-theme considers when and how best interests decision-making fails, with reference to legal, procedural, and systemic barriers.

Conclusions
Our findings suggest that the short title of the project – BABEL – was well-chosen, since they resonate with a narrative contained in the Christian Old Testament and the Hebrew Bible, which provides an origin story for why the world contains so many different languages. According to this theological narrative, humans originally all spoke the same language, but God condemned them to speak different languages, which rendered them less able to understand one another. The polysemy and pluralism of "best interests", as conveyed by our diverse participants, seems to echo this narrative, and our findings also echo those of previous empirical studies of such decision-making. There have been proposals to refine or replace the existing standard, for example, with an approach that emphasises the views of the person themselves (at least where adults are concerned) or alternatively with an approach that empowers parents to decide, unless they are making a decision that would be significantly harmful to their child. It remains to be seen, however, whether "best interests" should be replaced or whether its familiarity and flexibility means it should be retained.

3.5.2

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Support for family caregivers in Day Hospital in palliative care: vulnerability and power of grief

Background and issues
Providing support at the end of life increasingly requires coordination between hospitals and home, as well as a strong commitment from family caregivers. The experience of these caregivers in accompanying their loved one to the end of life, and then in mourning, questions the global approach to palliative care. In this perspective, a palliative medicine day hospital project has focused on supporting caregivers and the ethical issues that emerge: how can the experience of caregiving at the end of life help to identify the needs and resources of a palliative medicine day hospital?

Methodology
Collaborative research from an interdisciplinary perspective (ethics, philosophy, design and medicine) mobilized various actors concerned by the experience of caregiving at the end of life: 8 family caregivers, 6 months to 2 years after the death of their loved one, 5 professionals working in palliative care. The collaborative research was based on 3 phases: first, we conducted semi-structured interviews. Then, co-design workworps reunited all the actors involved in en-of-life care. And finally, an evaluation of the process is planed.

Results and discussion
The presentation of results will focus on the semi-structured interviews conducted prior to a co-construction process involving participatory workshops. The aim was to explore each person's individual experience in order to bring out the ethical issues of caregiving. The analysis enabled us to question the way in which people mobilize their experiences of caregiving, from the point of view of both family caregivers and healthcare professionals. The experience of end-of-life care for the family caregivers allows us to explore the dynamics of the experience of vulnerability: bereaved discourses are then marked, almost paradoxically, by an ability to mobilize powerful resources.

Perspectives
At the heart of shared vulnerability, attentive listening to these discourses is a prerequisite for a fruitful dialogue between caregivers and healthcare professionals, in order to move towards the joint constitution of a care community, within the innovative structure represented by the day hospital. The ethical reflection is fundamental and transversal for it constitutes a perpetual attention to participation during all the process, about sensitive topics and experiences. The way that grief affects family caregivers such as healthcare professionals requires a specific attention to experiental knowledge, narration and actions.

3.5.3

Jordan A. Parsons, University of Birmingham, Birmingham Medical School, Birmingham, United Kingdom

Best Interests and Rotten Compromise: exploring the instrumentalisation of P
In best interests decisions, the Mental Capacity Act 2005 (England and Wales) affords the person"s (P's) family a consultative role – they act as "consultees" to support the decision. That is, the decision does not fall to the next of kin but is made by the responsible clinician (unless there is an in-force lasting power of attorney for health and welfare). Evidence suggests, however, that where there is conflict between clinician and family it will often be the decision of the family that prevails. This remains true where the clinician considers the family"s favoured course of action in some way harmful to P. Clinicians often present this as compromise, led by a desire to placate the family and avoid heightened conflict and court proceedings. However, where the resulting care is harmful to P, we must question whether maintaining a good relationship with the family ought to be prioritised or even influential.
Drawing on Margalit"s (2013) conceptualisation of "rotten compromise" and applying it to the best interests context, I argue that there must be limits to how much best interests decisions should be affected by a desire to maintain a relationship between clinician and family. What we might call rotten medical compromise in best interests decisions is ultimately an instrumentalisation of P to appease the family. That is, what the clinician considers to be in the best interests of P is set aside to avoid escalating conflicting and risking Court of Protection involvement. As much as clinicians might be thought of as also treating the family, this should not come at the cost of harm to a vulnerable individual. Institutional supports are thus necessary to empower clinicians to prioritise the best interests of P over their family, in line with the 2005 Act.

3.5.4

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One big juggling act: Developer perceptions on the ethics of tracking devices in dementia care.

Background
The rise in using location tracking technologies, such as GPS watches, to mitigate the risks of dementia-related wandering has sparked ethical debates. Research has primarily focused on end-user perceptions, acceptability and adoptability, and the ethical implications of device use. The role of design and development in the ethical impact of these devices is less scrutinized, despite the increasing recognition that design and development play an important role in the ethics of technology. Few studies have explored the ethical perceptions of locator/tracking device developers, and this study aims to fill this gap by interviewing developers to better understand their perceptions on the ethics of locator/tracking devices in dementia care.

Research question
How do developers of electronic tracking devices perceive ethical issues surrounding the design, development, and use of electronic tracking devices within dementia care?

Methods
This study utilized a qualitative semi-structured interview study design, based upon a constructivist account of grounded theory. The data analysis process followed the Qualitative Analysis Guide of Leuven.

Results
Interviews with 15 developers, including 9 from commercial and 6 from university settings, revealed a strong feeling of moral responsibility to leverage their expertise to create better devices that improve the lives of persons with dementia and caregivers. Tracking device use was justified based on their ability to provide the best benefit-to-burden ratio compared to alternatives. During development, participants pursued moral and technical goals, and this involved navigating tensions between various ethical and non-ethical values. Developers relied on stakeholder inclusion, organizational mission, and domain experts to navigate these tensions. Pressures, such as resource limitations and profitability demand, greatly influenced decision-making. Developers felt a stronger moral responsibility in areas they perceived as within their control, such as designing to avoid problems or communicating proper device use, and felt a weaker sense of moral responsibility in areas outside their control, like device use.

Discussion
Developers integrate ethical decision making with development and business considerations. While perceiving a sharp divide between design and use, participants experience points towards this division being more porous. Future research should focus on scaffolding the ethical work already being done in development, such as stakeholder involvment.

3.6.1

Lydia Ariffin, University of Bristol, Centre for Ethics in Medicine, Bristol, United Kingdom

Exploring the Experience and Perspective of Practice, Teaching and Learning of 'Informed Consent' in the Malaysian Clinical Settings: A Qualitative Study

Background
Competency in obtaining informed consent is a fundamental clinical skill that advocates structured medical training. Despite its critical importance, existing literature reveals the lack of adequate education programmes in this field and is specifically absent in the Malaysian context. Studies also indicate a gap between theoretical comprehension and practical application of 'informed consent' in a clinical setting. This qualitative study is part of a PhD research project that aims to develop an educational framework for informed consent in a clinical setting in Malaysia.

Objective
This qualitative study aims to investigate and document the experiences and perspectives of key stakeholders engaged in the teaching, learning, and application of 'informed consent' in a clinical setting in Malaysia.

Methods
This research, which spanned over two public universities and four public healthcare institutions in various clinical settings in Malaysia, employed a semi-structured interview approach. Participants encompassed individuals at different stages of clinical experience, including medical students, house officers, junior and senior medical officers, clinical specialists, and medical lecturers (n=25).

Results
The experiences and perspectives of the participants were systematically categorised into four main themes: knowledge and understanding, practice, teaching, and learning. The study identified a significant knowledge and understanding gap among participants concerning 'informed consent' and the legal requirements associated with consent in a clinical setting. Most participants exhibited a foundational understanding of 'informed consent' but were not able to describe the criteria for valid consent comprehensively. While more than half received training, at either the undergraduate and/or postgraduate level, it primarily consisted of brief lectures, with no or minimal practical sessions. The majority acquired the practical skill of obtaining consent through observational learning from senior medical officers and clinical specialists as they entered the service upon graduation. In practice, challenges arose when doctors lacked a solid foundation in consent knowledge, highlighting the necessity for robust training. Current teaching methods predominantly involve didactic lectures, with some supplementing tutorials and minimal practical sessions.

Conclusion
This qualitative study offers vital insights into participants' experiences and perspectives regarding the depth of basic understanding, practice, learning, and teaching of 'informed consent'. The findings underscore significant deficiencies in participants" knowledge and teaching methodologies associated with 'informed consent'. There are concerns that unstructured observational learning in clinical settings may lead to outdated and unethical practices, incomplete coverage of topics, substandard educational experiences, and unequal learning opportunities.

Implications
The findings of this research highlight the urgent need for an educational framework dedicated to teaching informed consent. The aim is to enhance knowledge and elevate practice standards in obtaining informed consent within the Malaysian healthcare landscape.

3.6.2

Annett Wienmeister, Charité Berlin, Germany, Institute for the History of Medicine and Ethics in Medicine, Berlin, Germany

How about a (tiny) little bit of informal logic? Promoting moral reasoning skills in students through argumentation theory as a means to translate ethics into healthcare practice

Moral reasoning skills are a key feature of ethical competency in health professions. While it is difficult to present a clear-cut definition of the term "ethical competency", several concept studies have found main elements that are repeatedly related to ethical competency in the health professions literature. Amongst them are moral reasoning skills. Others are ethical awareness, ethical knowledge, ethical decision-making, character strength, ethical behavior and ethical action. Along with the importance of promoting ethical competency in health professions, the demand of students to acquire moral reasoning skills is widely acknowledged. More specifically, students of health professions are expected to learn how to recognize an ethical question or problem and to take different perspectives on it. Furthermore, they are supposed to critically reflect on those ethical questions or problems, which is often framed as an ability to justify their own viewpoint and to respond appropriately to objections.

These learning objectives concerning moral reasoning abilities in students are quite demanding. At the same time, instructors of ethics in health professions have difficulties to translate them into specific exercises as well as to choose appropriate methods for teaching and assessing moral reasoning skills. When it comes to methods, didactics literature often suggests and evaluates methods that promote cognitive and discursive development, such as the use of group discussions, case studies and ethical decision-making models. It is intuitively clear that all these formats and models can promote moral reasoning skills in one way or another. However, without further explication, it remains obscure what exactly it means to justify one's own viewpoint and how to evaluate objections. In addition, it is not clear at all how to best support students in acquiring the corresponding competencies. After all, it is difficult to teach what has not been clearly defined. This lack of clarity might explain why students often comment that ethics discussions, while very interesting, leave them confused or with the impression that one opinion merely stands against another.

In my oral presentation, I will therefore ask how one can more closely define moral reasoning skills in health professions in order to facilitate instructors to teach them to students. In a first step, I will refer to the philosophical disciplines of informal logic and argumentation theory in order to give a definition of the term "argument" as a way to define what it means to justify one's viewpoint. In a second step, I will present quality criteria from these disciplines that help evaluate and critically discuss arguments. In a third step, I will frame the definition and the quality criteria such that they can be integrated into ethic courses, paying attention especially to time restrictions that instructors often face. I will do so by formulating short maxims that instructors can follow when planning exercises and choosing methods in order to promote moral reasoning skills in their students. An example from a possible ethics discussion with students in class will help illustrate the benefits of this approach. In a last step, some of the challenges of translating ethics into healthcare practice by introducing a tiny little bit of informal logic into health professions ethics classes will be discussed.

3.6.3

Jenny-Victoria Steindorff, University Medicine Halle, Medical Faculty of the Martin Luther University Halle-Wittenberg, Health Service Research Working Group Care in the hospital, Department of Internal Medicine, Halle (Saale), Germany

Embodiment as a resource for person-centred and ethical value-based care in the light of VR-supported nursing training.

"Values play an important role in how we understand, make sense of, and tackle crises" (EGE, 2022).

In times when healthcare systems increasingly have to respond constructively to crises such as the Covid-19 pandemic or disruptive developments such as digitalization and the growing importance of Artificial Intelligence, values are once again gaining in significance as a guiding principle. The professional ethical values represented by nurses, such as respect, empathy or benevolence (ICN, 2021) should therefore go beyond the goal of reducing costs and instead create (intangible) values for patients, as measured objectively in PROMs and PREMs, but also experienced subjectively.

An essential prerequisite for this is person-centered care, which asks whether a nursing intervention is the right thing for this person, at this time and in this setting (Gilmore et al. 2019). The basis for this is an approach to the patients that allows the identification of their specific needs and requirements. The embodied sense of the subjective world of life and experience of those affected represents such an approach. It provides essential access to a critically reflective and professionally orientated way to deduce care activities tailored to individual needs and requirements. Furthermore, it refers to the acknowledgement that patients, not providers, know themselves best and the realization that quality care can only be achieved when patients and their individual preferences are integrated into decision making and care (Salmond & Echevarria, 2017). However, the cognitive-rational level is not always the only way to explore these wants and needs of patients, but can and should be accessed in other ways, like through embodiment, for instance.

Apart from this, the path to the declared goal of nursing training "to develop and strengthen a professionally ethical understanding of nursing and a professional self-image" (§5, Para. 4 PflBG) is experiencing a new openness in its operational and didactic-methodologically design. As a result, the use of digital media such as Virtual Reality (VR) is also increasing. With the help of authentically designed case studies, VR offers trainees a helpful training and reflection basis to support the acquisition of nursing-relevant skills, for example through a change of perspective.

But despite the parallel call for care professionals to acquire future-oriented digital skills (KMK, 2016), it is important to discuss the following questions:

- Is it possible to use VR in vocational training to depict a person-centered and ethically reflective approach, which caregivers and care recipients can experience directly by the embodied sensation?

  and:

- Is VR a suitable way to sensitize trainees with regard to the necessary closeness and reflection of their everyday approach, especially away from routines but in consideration of ethical values?

Therefore, this presentation will outline the initial results of the question, whether VR represents an opportunity or rather a limitation for this purpose in the context of German nursing training.

3.6.4

Lukas Kiefer, University Hospital Heidelberg, Heidelberg University, Section for Translational Medical Ethics, NCT Heidelberg, Heidelberg, Germany
Eva Winkler, University Hospital Heidelberg, Heidelberg University, Section for Translational Medical Ethics, NCT Heidelberg, Heidelberg, Germany

Translating ethical fiduciary concepts into health research: How can data fiduciaries contribute to a trust architecture for the research use of health data?

Background

By applying "data trust" or "data fiduciary" models to the research use of health data, ethical fiduciary concepts gain importance in the health research sector.
Data fiduciary models have been suggested by expert and ethics councils for protecting patients' rights while simultaneously enabling data usage: The German Ethics Council describes the data fiduciary as an intermediary between data subject and data user, that should be installed to foster trust and to prevent misuse. Data fiduciary concepts could help to reduce the imbalance of power and to prevent conflicts of interests. The potential of such models has also been recognized by the German government, which states in its coalition agreement and digital strategy the goal of establishing data fiduciary models.

Ethical challenges

Despite multiple recommendations for implementing data fiduciaries, there is no common understanding of the term data fiduciary and the underlying ethical concept. The term is currently used indiscriminately for more complex proxy constructions as well as very simple IT applications. This is problematic, as some of the models do not meet the criteria for a fiduciary relationship and expectations generated by the trust-provoking labelling "fiduciary" might be disappointed.
Therefore, a foundation of the concept of data fiduciaries and an identification and elimination of misnomer is essential to successfully implement the concept of data fiduciaries in health research. This is the focus of our project "Data fiduciaries in medical research: ethical and legal foundations and implementations."

Approach and Discussion

An ethical fiduciary concept is characterized by following attributes: A fiduciary is entrusted with discretionary power over practical interests of another person (the beneficiary). The fiduciary is typically characterized by special expertise, which he uses for the benefit of the beneficiary. The relationship between fiduciary and beneficiary is characterized by vulnerability and dependency of the beneficiary and based on a special trust. The fiduciary is bound by special duties – the fiduciary duties – which are often summarized under the terms duty of loyalty, care, and good faith.
While the fiduciary concept is well established in other areas of healthcare (e.g. physician-patient relationship), multiple data fiduciary concepts do not fulfill the mentioned requirements. This includes simple data repositories or storage services, pseudonymization services or personal information management systems (PIMS).

Conclusion

A well-founded data fiduciary concept with defined roles and duties of the stakeholders has the potential to fulfill hopes associated with the terms "data fiduciary" and "data trust". However, in the current discussion, models are labelled as data fiduciaries that do not meet the corresponding requirements. A reconsideration of the essential elements of a fiduciary relationship is necessary in the design of potential data fiduciary models (e.g. German research data centers) and data initiatives (e.g. Medical Informatics Initiative (MII), The German Human Genome-Phenome Archive (GHGA), 1+ Million Genomes initiative).

4.2.1

Szilárd Dávid Kovács, Semmelweis University, Institute of Behavioural Sciences, Budapest, Hungary

Pioneering a Novel Unified, Quantitative-Qualitative Method for Heightened Argumentative Rigor in Bioethical Dilemmas

In the past, bioethics has mainly depended on theoretical arguments for its inquiries. However, recognizing the importance of sociocultural factors in tackling complex ethical issues in practical settings, bioethics has increasingly integrated empirical research alongside theoretical discourse. Qualitative empirical studies have proven effective in exploring new territories by revealing patterns in experiences and perspectives. Despite the merit of qualitative studies in bioethics, a common limitation lies in the lack of clarity in the methods sections regarding the codebook and code application. However, enhancing openness is essential for public scrutiny of data interpretations. Moreover, in studies employing thematic analysis, where code co-occurrences hold meaning, identifying these co-occurrences across multiple data providers poses a significant challenge. To address these challenges, Computer-Assisted Qualitative Data Analysis Software, such as Epistemic Network Analysis, can generate quantitative models of coded data, producing coordinated network visualizations of code co-occurrences for individuals or groups of data providers.

The objective of my project is to introduce a novel method in bioethics utilizing quantitative modeling of code co-occurrences. It conducts exploratory research on the conflict between patient autonomy and nonmaleficence, observed in scenarios like medical aid in dying, or requests for body modification, with a specific focus on this ethical challenge within the field of dentistry. While life and death issues are uncommon in oral care, patient request is a factor in a significant proportion of tooth extractions, dentistry faces a rise in demand for cosmetic procedures, and literature describes correlation between orofacial appearance and psychosocial well-being. Existing studies in this domain are largely theoretical, thus the field lacks comprehensive mapping and framing. In my prospective plans, my aim is to utilize the results from this empirical study alongside a scoping review of relevant literature on the researched ethical dilemma, intending to compare and contrast the empirical results with existing theories via wide reflective equilibrium.

The study involved interviews with 20 dentists and 20 patients, exploring their encounter with the ethical dilemma and illustrative situations in literature. Proportional quota sampling, incorporating criteria of sex and age for the patient subsample, and sex and leadership experience for the dentist subsample. Codes were developed inductively by two coders and are currently being systematically applied to the entire dataset at the level of sentences.

To assess the feasibility of the method, preliminary coded data was tabularized, and epistemic network models were constructed. Initial analyses of the networks showed that both patients under the age of 35 and dentists in all groups demonstrated a high frequency of co-occurrence between the codes representing esthetic outcome and medical indication. This pattern suggests a receptiveness to cosmetic procedures when deemed medically viable in both cohorts, aligning with ethical theories proposing that a patient's medical interest and personal desires are interdependent values. Conversely, patients in higher age groups exhibited a more interconnected network, where the prestige of the medical profession played a significant role in decision-making, implying acceptance of a more paternalistic approach. Interestingly, this inclination was not mirrored by the dentists themselves.

In conclusion, this project advocates for the use of quantitative models to enhance the robustness of statements, improve transparency, and facilitate peer scrutiny. Access to detailed models of individual and group narratives empowers researchers to integrate empirical results into normative argumentation more effectively regardless of their paradigm and how they bridge the gap between descriptive and normative.

4.2.2

Felix Tirschmann, Protestant University Ludwigsburg, Health Sciences, Ludwigsburg, Germany
Kirsten Brukamp, Protestant University Ludwigsburg, Health Sciences, Ludwigsburg, Germany

Qualitative methods in participatory research and development projects for health technologies

Qualitative methods are frequently used in participatory research. In the context of interdisciplinary research and development projects, participatory approaches for responsible health technologies are becoming increasingly relevant. Consequently, qualitative methods will gain further importance in the interdisciplinary collaboration between the technical, social, and health sciences.

In participatory technology development, the use of qualitative methods is particularly useful for identifying ethical, legal, and social implications (ELSI) of health technologies. For example, interviews, focus groups, and workshops help to explore different user perspectives on innovative health technologies and to integrate the findings into responsible innovation.

The use of qualitative methods for participatory research projects on health technologies possesses several challenges. At the level of data collection, the inclusion of vulnerable user groups presents research ethics challenges to qualitative researchers. At the level of data evaluation, methodological challenges concern the applicability of results from qualitative research for technology development.

Various approaches have proven successful in solving these challenges in research practice. With regard to data collection, the reviews of study protocols by research ethics committees promote the ethically responsible conduct of trials. During data evaluation, descriptive and content-analytical methods lead to comprehensible, rule-based, and intersubjectively validated research results.

Participatory research projects should be conducted in an ethically responsible manner, and their results should be communicated for interdisciplinary contexts, based on the exchange with potential user groups. The key components for the success of participatory technology development are the translational processes of research-relevant and experience-based knowledge between experts and laypersons on the one hand and the disciplines, professions, and organizations involved on the other hand.

Several research and development projects serve as examples for the interplay between participatory research, qualitative methods, and responsible technology development. These studies include diverse technologies, such as artificial intelligence and clinical decision-support systems. The examples demonstrate the benefits of qualitative research for ELSI in participatory technology projects and present solutions for overcoming translation problems in research and development.

4.2.3

Silviya Aleksandrova-Yankulovska, University of Ulm, Institute of the History, Philosophy and Ethics of Medicine, Ulm, Germany
Florian Steger, University of Ulm, Institute of the History, Philosophy and Ethics of Medicine, Ulm, Germany

The role of qualitative research in translating ethics within the area of fertility protection

Background
Issues of progressively decreasing fertility, especially in developed countries, have been a hot research topic for specialists in different areas for several decades already. However, fertility protection alone is one still novel research area. Our paper is based on the Federal Ministry of Health (BMBF) funded interdisciplinary project for establishment of Fertility Research Center for fertility protection in Ulm (FePro-Ulm). The project is coordinated by Prof. Dr. Katharina Hancke and PD Dr. Dr. Karin Bundschu and involves research groups with backgrounds in obstetrics and gynecology, pediatrics, haemato-oncology, psychosomatic medicine and ethics.

Methodology
The *aim* of our paper is to present the goals and the added value of the ethical sub-project implemented by the Institute of History, Philosophy and Ethics in Medicine, University of Ulm, thereby elucidating the role of qualitative research in translating ethics in research on fertility protection. In order to support and ethically evaluate fertility protection technologies will first apply systematic literature review followed by qualitative research through semi-structured interviews. The latter will cover representatives of different stakeholder groups: professional experts and patients. The patients" sub-groups cover on one side women and men before oncological treatment and on the other side, transgender people in need of transitional care.

Results
The goal of the ethical sub-project of FePro is to provide systematic and in-depth knowledge of the ethical, social and normative challenges accompanying the methods of fertility protection. Ethics issues within several areas will be investigated through experts" and patients" opinions: a) benefits and risks assessment of the technology; b) particularities of informed consent; c) responsible handling of personal data; d) freedom of decision-making in view of the social and family interests at stake; e) challenges arising from different regulatory frameworks; and f) issues of justice in regard to the access to reproductive technologies. The wide subjects" inclusion in the research is expected to provide new valuable insights towards the development of reproductive technologies of fertility protection incorporating the expectations and values of the main users" groups.

Conclusion
The rapid development of our abilities to intervene into human reproduction combined with the unfavourable fertility trends raises more and more ethical questions. Traditional theoretical ethics works keep playing important role in shaping ethical trends but they fall short in addressing patients" perspectives. Thus, qualitative research methodologies remain indispensable in translating ethics into research and clinical practice, since both fields look more for empirical data than for theoretical foundations.

4.3.1

Suzanne Metselaar, Amsterdam UMC Medical Centers, Ethics, Law & Humanities, Amsterdam, Netherlands

Translational Bioethics as a Two-Way Street. Developing Clinical Ethics Support Instruments with and for Healthcare Practitioners

Question

How can "translational bioethics" be understood?

Methods

Analysis of different concepts of translational bioethics, argumentation for a new approach to translational bioethics, illustrated by an example from research (the CURA project).

Results

In my presentation, I will propose a new approach to translational bioethics (TB), in line with my recent article "Translational Bioethics as a Two-Way Street. Developing Clinical Ethics Support Instruments with and for Healthcare Practitioners" (*Bioethics*, 2023).
I will shortly address and evaluate existing approaches to TB, and argue why some of them are problematic. Subsequently, I will propose a new approach to TB. This approach is concerned with the adaptation – or "translation" – of concepts, theories and methods from the domain of academic bioethics to practical contexts, in order to support "non-bioethicists", such as researchers and healthcare practitioners, in dealing with their ethical issues themselves. The theoretical underpinnings of this participatory approach to TB are found in hermeneutic ethics and pragmatism.
As an example of this approach to TB, I will go into the participatory development of clinical ethics support (CES) instruments that respond to the needs and wishes of healthcare practitioners, and that are tailored to the specific care contexts in which they are to be used. In collaborating with healthcare professionals, the bioethicist may bring to the table existing ethical concepts, theories and approaches to CES. Practitioners may bring in their wishes, needs and limitations, but also their knowledge of the ethical challenges and practical premises of their clinical field.
Specifically, I will go into the development of CURA, a low-threshold CES instrument for healthcare professionals in palliative care. "CURA" was co-created by ethicists/researchers together with various stakeholders from different palliative care settings. Existing approaches to moral reasoning and CES were rigorously adapted through various cycles of co-creation, piloting, and evaluation into a CES instrument consisting of four main steps: Concentrate, Unrush, Reflect and Act.

Conclusions

From this example, it becomes clear that TB is a two-way street. Practice may be improved by means of CES that is effectively tailored to specific end users and care contexts. The other way around, ethical theory may be enriched by means of the insights gained from engaging with practice in developing CES in a process of co-creation. TB is also a two-way street in the sense that it requires collaboration and commitment of both bioethicists and practitioners, who engage in a process of mutual learning.
However, substantial challenges remain. For instance, is there a limit to the extent to which a method of moral reasoning can be adapted in order to meet the wishes of practitioners and/or the constraints of a given health care setting? Who is to decide, the bioethicist or the practitioners?

4.3.2

Katharina Rockmann, University of Augsburg, Medical faculty, Institute of Ethics and History of Health in Society, IEHHS, Augsburg, Germany

An argument in favour of a modified Four-Topics-Model in Ambulant Ethics Consultation

Clinical Ethics Consultation (CEC) has become a routine provision in hospitals in Germany. In the ambulant setting, Ethics Support is also positively rated by users and supported by medical associations. Though several methods of ethical reasoning have been evaluated for CEC in hospitals, there are only scant reports about models applied in the ambulant sector.

In this presentation, I will first argue that Ambulant Ethics Consultation (AEC) at the patient's home features distinct descriptive and prescriptive characteristics. These give rise to conceptual considerations, e.g., who is asking what kind of ethical question, who is attending the meeting and who will eventually decide upon the course of action, but also to more substantive thoughts, such as an argument in favour of a family ethical perspective in which relationality is emphasised.

I will further argue that a modified version of Jonsen's original Four-Topics approach represents a robust and viable method of moral reasoning in AEC, accounting for distinct features and conditions in outpatient care. The original Four-Topics approach, introduced by Albert R. Jonson in 1982, represents a systematic deductive model of ethical reasoning that translates general principles into concrete clinical practice. It has primarily been used in the US for in-hospital CEC; little is known about its practical application in Germany / Europe and its employment in the ambulant setting. The proposed model builds a procedural framework around prima facie ethical principles that will be further supplemented by context-specific considerations. It represents a systematic step-by-step model, addressing four major topics, intelligibly progressing from abstract conceptions to concrete action guidance. The four categories "medical indication/treatment options", "patient's preferences", "quality of life", and "contextual features" are value-centred but simultaneously context-sensitive and reflective of clinical practice. Thus, by framing substance, process, and language, the proposed modified Four-Topics model is responsive to particular needs and circumstances in complex decision-making when the patient/proxy/family, the General Practitioner, and other formal or informal caregivers are involved and helps to find the best course of action through good ethical reasoning.

As a palliative care physician working in the ambulant field, I would like to emphasise the conceptual significance of the proposed model, particularly in end-of-life decision-making. In view of its practical application, we have already had some positive experiences using it for our recently implemented ambulant ethics consultation service.

4.3.3

Julia Inthorn, Lutheran church of Hannover, Center for Health Care Ethics, Hannover, Germany
Nikolai Münch, University Medical Center, Mainz, Germany

Models of Clinical Ethics Consultations as translational tools
Bridging the gap between ethical expertise and clinical practice

The concept of expertise is more contested in the field of ethics than it is in perhaps any other discipline. While many readily accept expert advice in a wide variety of fields, e.g., tax law or cardiology, they may still harbor significant skepticism towards moral guidance provided by ethicists. Therefore, an ongoing debate persists regarding the fundamental nature of ethical expertise, and its role in healthcare. Explorations into ethical expertise have primarily focused on theoretical issues like the nature of ethics and morality, considerations in metaethics and epistemology.

In clinical practice, however, one of the most important ways of "doing ethics" are ethics consultations. Ethical expertise is particularly essential here, albeit not only (and arguably not even mainly) in the sense of academic philosophical ethics expertise. In Germany there are two approaches to establishing benchmarks for the quality of ethical decision-making. These approaches focus on either individual expertise through training, or on suggesting guidelines and models for ethical consultations.

Various models have been developed in order to structure moderation and consultation of ethical deliberations in hospital settings. Each model contains a structured process, suggestions for specific questions to ask participants, and a mode of decision-making based on consensus among all participating professionals and patients and their representatives. Many models also provide concrete linguistic formulations and terminology suggestions to clearly describe normative assessments in case deliberations. For this reason, these models are often implemented as a means to ensure all pertinent issues are discussed, and that medical procedures are chosen that make ethically desirable outcomes more likely. These models are meant to facilitate the transfer of ethical expertise directly into everyday clinical practice.

Despite current safeguards, important aspects of the decision making process remain overly vague, like the weighing of individual principles or evaluation of courses of action. Furthermore, the relation between individual expertise and procedural standards seems open for debate. In this presentation, we take theoretical models of expertise as well as examples of good decision making from clinical practice as a starting point to analyze different models of ethical consultations. We focus on the following two questions:

1. What understandings of ethical expertise do different models reflect?
2. How do models support capacity-building, training, and visibility of ethical expertise and what are the limitations of consultation models?

Based on the results we discuss, what aspects of ethical expertise are not easily standardized through those models, and therefore need to be integrated into practice through other means.

4.3.4

Marleen Eijkholt, LUMC, Leiden, Netherlands
Janine de Snoo-Trimp, LUMC, Leiden, Netherlands
Sara Court, LUMC, Leiden, Netherlands and Amsterdam UMC, Amsterdam, Netherlands
Bert Molewijk, Amsterdam UMC, Amsterdam, Netherlands

Patient participation in clinical ethics interventions: Justifications and risks – an international study.

Patient participation in clinical ethics interventions (CEI) occurs in 73–96% of the cases in the USA, according to a recent study. But patient participation in CEI (hereafter: PP) seems much less common outside of the US. In Europe, for example, PP seems rare. A study in the Netherlands revealed concerns about risks of harm the patient physician relationship or a confusion in responsibilities as reasons to object to PP.

Recently, we conducted an international survey querying the reasons for or against patient participation, in different parts of the world. We also asked about the obstacles preventing PP and perceived needs to address any concerns.

In our analysis for this presentation, we zoom in on objections against PP, based on perceived risks and harms. We ask if these can be upheld in the light of the empirical and theoretical considerations that justify PP. In our analysis we consider if solutions would be available to address risks that we consider reasonable. We seek to go beyond arguments about cultural differences.

4.4.1

Giovanni Spitale, University of Zurich, Institute of Biomedical Ethics and History of Medicine, Zurich, Switzerland
Federico Germani, University of Zurich, Institute of Biomedical Ethics and History of Medicine, Zurich, Switzerland
Nikola Biller-Andorno, University of Zurich, Institute of Biomedical Ethics and History of Medicine, Zurich, Switzerland

WHO leads the way? Bridging ethics and practice in social listening and infodemic management

In light of the critical importance of ethical considerations in healthcare, particularly during public health emergencies, this conference contribution will focus on detailing the journey and insights gained from the creation of the WHO guidance document on ethical infodemic management. Specifically, it will explore the process of developing a framework that is both theoretically solid, rooted in the human rights framework, and practically usable by diverse stakeholders, translating principles into actionable goals.

Crafted for a diverse audience, including health authorities, public health professionals, and tech companies, the guidance emphasizes the importance of ethical practices in social listening and infodemic management. It highlights the ethical challenges posed by these activities, presents a set of substantive and procedural principles, and practical, actionable guidance for the implementation of principles into practice.

This document seeks to bridge the gap between theoretical ethical considerations and the day-to-day realities of healthcare practice. By doing so, the WHO highlights the crucial role that ethical guidance should play in informing policies and guidelines across all levels of healthcare – at a global scale.

The discussion will emphasize the importance of interdisciplinary collaboration in crafting ethical guidelines that are both comprehensive and applicable. The role of evidence, ethical expertise, the engagement of stakeholders across healthcare, public health, and technology sectors, and the iterative process of refining the guidance based on feedback and real-world applicability will be explored.

This contribution seeks to not only share a specific case study on ethical guideline development but also to stimulate broader discussion on the role of ethics in healthcare decision-making. It aims to encourage dialogue among conference attendees on the challenges and opportunities of translating ethical principles into policies, with the ultimate goal of fostering a healthcare ecosystem that is ethically responsive and responsible. Through this, the presentation aspires to contribute to the ongoing conversation about how we can better bridge the gap between ethical theory and healthcare practice, ensuring that ethical considerations are not just an afterthought but a foundational aspect of healthcare policy and practice.

4.4.2

Mirko Ancillotti, Uppsala University, Centre for Research Ethics & Bioethics, Uppsala, Sweden
Deborah Mascalzoni, Uppsala University, Centre for Research Ethics & Bioethics, Uppsala, Sweden and Eurac Research, Institute of Biomedicine, Bolzano, Italy

Development of a public health ethics framework for lighting

Over 80% of the world's population lives under a skyglow dome — an effect of artificial light at night (ALAN) raising sky luminance — topmost in North America and Europe, where only 1% can see a completely natural sky at night. This is problematic in many respects.

ALAN poses ecological concerns due to its direct impact on fauna and flora — such as influencing movements, foraging, and communication — and indirectly through its contribution to global electricity consumption and greenhouse gas emissions. Excessive light affects physiology and behaviour, including entraining circadian rhythms and affecting melatonin production. The scientific evidence suggests that the role of melatonin is not limited to sleep disorders, but it may affect an array of biological functions and processes, including cancer, metabolic, cardiovascular, and neurodegenerative disorders. The absence of darkness raises essential issues of heritage and tradition preservation, as well as questions about darkness significance in the human experience of self and perception of reality. Moreover, lighting hugely contributes to shaping public spaces and social life. In urban contexts, light impacts security, sense of safety, and trust in the city and its citizens. As such, lighting is a decisive feature in determining spatial equity. Consequently, while there is a call for decreased lighting due to its adverse effects on human health, ecology, economy, intergenerational justice, and human experiences of darkness, concerns regarding security, safety, and accessibility often oppose such measures.

As concerns over excessive lighting — often framed as light pollution — are morally loaded and primarily conceived as an environmental issue, environmental ethics is an adequate arena to discuss excessive and improper lighting. However, the environmental ethics context requires considering the effects of excessive lighting on human health as a facet of a broader problem and balancing human interests against those of other entities, as they would be intertwined with concerns over animal and environmental harm. This is not wrong, but it only marginally accounts for the magnitude and potential severity of the problem for human health. While it is acknowledged that various ethical fields should interconnect to foster a healthier planet for all, excessive and improper lighting poses a direct and immediate risk to human health, which warrants its ethical discussion also outside of the environmental tradition.

We advocate for public health and public health ethics as key arenas for addressing lighting-related concerns along with those already existing. Public health ethics is intended to comprise ethical issues relating to societal activities that can be described as public health, as in the case of lighting. Two distinctive characteristics of public health ethics are the focus on the health of populations and the prominent role of government. As public health takes the population perspective, its ethical dimension often implies a dilemma between individuals, or sometimes groups, and the larger community benefit. While government intervention is not always necessary, coordinating various actors is frequently crucial for achieving positive public health outcomes. These distinctive characteristics involve the need for public health activities to be continuously evaluated and justified from an ethical standpoint and to assist policy-makers and administrators with purpose-built ethical means to inform their decisions.

We aim to map ethical principles relevant to lighting initiatives. The intention is not to prescribe how these principles should be prioritised or applied in decision-making, as such a task could only be performed with a proper appraisal of the context in which they are applied, but to provide a framework of ethical reference to support policy and decision-making.

4.4.3

Sara Köthemann, University Medical Center Göttingen, Department of Medical Ethics and History of Medicine, Göttingen, Germany
Marion Schmidt, University Medical Center Göttingen, Department of Medical Ethics and History of Medicine, Göttingen, Germany
Claudia Wiesemann, University Medical Center Göttingen, Department of Medical Ethics and History of Medicine, Göttingen, Germany

The concept of ethical governance and its translation into health care practice: Conceptual and empirical insights taking patient organizations as an example.

Health care organizations deal with one of the highest goods – health – and take care of people in vulnerable situations. They are thus, rightly, held to specifically high ethical standards. Thus, it is not surprising that there has been a growing interest in recent years in ethical governance for health care organizations. In fact, ethical governance has become a buzzword in the literature. Yet, at the same time, it remains a vague concept, mostly referred to without a grounded understanding of its significance, implications and shortcomings.
In our talk, we address ethical governance both as a philosophical concept and as a tool to guide health care organizations through complex ethical decision-making. Our approach is threefold. In the first part of our talk, we analyze the concept of ethical governance from a philosophical point of view taking into consideration its roots in business ethics and its translation into health care practice. We discuss the implications of the concept as well as its shortcomings.
In the second part, we illustrate the conceptual and practical challenges of this concept, by example of ethical governance in patient organizations. Patient organizations are important, yet often underappreciated agents in the health care sector. They act as advocates for patients and interact on multiple levels with other stakeholders in the health care system, navigating a complex web of ethically challenging relationships and cooperation. We present the findings of an empirical ethical study (website analysis and focus groups) of patient organizations" approach to ethical governance in regard to their digital services and activities.
In the third part, we are integrating philosophical analysis and empirical findings, and we demonstrate the importance of a well-understood and purposefully implemented concept of ethical governance. Specifically, we argue for an understanding that is substantiated by the values pertinent to the health care system. We show how clarifying and operationalizing ethical governance may help to ensure ethical behavior and thus sustain trust in health care organizations and the health care system.

4.4.4

Matthias Katzer, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany
Sabine Salloch, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany
Christoph Schindler, Hannover Medical School, Center for Clinical Trials, Hannover, Germany
Marcel Mertz, Hannover Medical School, Institute for Ethics, History and Philosophy of Medicine, Hannover, Germany

Systematic, but not quality-assessed? The problem of quality appraisal in systematic reviews of reasons – and a possible solution by applying basic argumentative standards

Question
Systematic reviews of reasons (SRR) map the reasons given in the literature for or against various answers to an ethical question. An important feature of systematic reviews in general is a quality appraisal of the found literature. However, many reviews in ethics tend to forgo this appraisal. Often, only rather pragmatic criteria (e.g. only including peer reviewed publications) are considered when in- and excluding literature. On the one hand, this has to do with the fact that normative literature cannot be tested for its (reporting) quality the same way as empirical studies and that proposals for assessing the quality of normative literature (e.g. scoring certain characteristics of an article) are confronted with many challenges. On the other hand, unsolved issues also occur when moving away from the quality of an article and focussing on the quality of the individual reasons. This is partly because a systematic, unbiased and feasible assessment of reasons seems to be difficult as well. Does this mean, as is sometimes argued, that the nomenclature "systematic review" must be abandoned because quality appraisal cannot be realized, or are there still prospects to implement it in an adequate form?

Methods
We present a possible solution by subjecting the included reasons to basic argumentative standards. In this way, quality appraisal is introduced at the step of literature analysis, not at the step of inclusion/exclusion of the literature. We have developed and tested this procedure in a SRR on the ethical requirements for human challenge studies (HCS). 161 articles were included in this SRR. HCS are experimental clinical trials in which subjects are intentionally infected with a pathogen. They raise a number of ethical concerns, in particular the acceptable level of risk to participants. As part of this review, we thus collected the different positions on acceptable risk in HCS and the reasons given for them. We then applied the following standards for good arguments to these reasons: (1) every reason must be logically independent from the requirement for which it is a reason, and (2) it must be a consideration in favour of this requirement. Furthermore, we checked whether any (systematic or anecdotal) external evidence was given for reasons referring to empirical claims. We also categorized the diverse ways in which reasons expressing normative claims are justified, e.g. via moral principles, reference to normative guidance documents, or (own) moral intuitions. However, we did not use the criteria to exclude reasons, but only to characterize them transparently.

Results
We found a large number of reasons for different positions on acceptable risk. For a considerable number of these, it is doubtful whether they meet the argumentative standards that we presuppose. Further, some empirical claims were poorly supported by evidence. As a consequence, many reasons from the debate appear to be weak. However, such judgments always rely on a certain interpretation of an argument in its particular context. Therefore, although the proposed method cannot solve the fundamental problem that one is confronted with when evaluating ethical reasons (or arguments), it can mitigate it in an acceptable way within the framework of an SRR: The reasons must at least satisfy such basic criteria as are accessible to average, academically experienced readers (esp. readers not trained in philosophy).

Conclusion
Our example shows that argumentative standards for reasons can be successfully integrated into the methodological framework of a SRR. However, applying them does not settle the question which reasons (e.g. on acceptable risks in HCS) are, all things considered, compelling. Nonetheless, it reduces the field of reasons given for different positions, which may well be a helpful function of an SRR for interested readers – and may be sufficient to defend the nomenclature.

4.5.1

Oliver Feeney, University of Tübingen, Institute for Ethics and History of Medicine, Tübingen, Germany

Genome Editing and non-ideal Justice: the case of Sickle Cell Disease (SCD)

Current innovations in genome editing have been steadily realising the once remote possibilities of making effective and realistic genetic changes to humans. This is most recently highlighted with the breakthrough of Casgevy - a CRISPR–Cas9 gene editing therapy to treat sickle-cell disease. As it moves from successful clinical trial stage to regulatory approvals in the US, UK and the EU, a focus on translational ethics can be widened to turn to questions of justice and access. The ongoing concerns of distributive justice regarding inequalities in the distribution of access to potential genome editing technologies is also highlighted with Casgevy – particularly notable by the expected two million Euro (plus) cost per patient for treating a blood disorder that is overwhelming bourn by the world"s less advantaged populations. Nevertheless, requiring an ideally just and egalitarian distribution of costly technologies may be an unrealistic ideal and the alternative of forbidding access to those able to meet the costs, when others cannot, is a very morally problematic substitute. Even if access could be sufficently widened for this, and for other high cost medical technologies, the next question has to be on how far should this access be prioritised over other allocations of finite healthcare resources. One outcome of this is a more nuanced response than some of the fears of a new kind of inequality in genetic healthcare arising. On the contrary, according to some non-ideal theory approaches, improving access for the worst off may result in – and encourage – increased inequalities in access to new genomic technologies, in order to incentivise innovation and increased development in the private sector, which is argued as vital for fostering high cost genomic technologies beyond the capabilities of the public sector . In this paper, I will highlight how this case futher challenges ideal theories in distributive justice and demands of equality, and emphasises the role of non-ideal theory, including examining a range of potential responses from the fields of patents and other public-private initiatives. While such responses will highlight some achievement in non-ideal justice, a number of fundamental issues remain to be addressed, including the seemingly ever shrinking domain of justice, the increasing – not always benign – influence of patents, and changing norms in science collaboration to for-profit motivations.

4.5.2

Karla Alex, Heidelberg University Hospital, Section Translational Medical Ethics, NCT, Heidelberg, Germany
Eva Winkler, Heidelberg University Hospital, Section Translational Medical Ethics, NCT, Heidelberg, Germany

Genomic Newborn Screening for Adult Actionable Conditions – Why Not?

Question
This talk assesses the ethical acceptability of genomic newborn screening (gNBS) for adult actionable conditions, which are conditions like Hereditary Breast and Ovarian Cancer syndrome for which preventive options should be started in adulthood. Thus, the talk asks: gNBS for adult actionable conditions, why not? Following our talk on problems associated with screening newborns for adult actionable conditions in gNBS, we hope for an engaged discussion due to the topicality of this issue. This will provide valuable insights for our own ethical research on gNBS programs.

Background
Newborn screening (NBS) programs are among the world's most successful public health programs. Despite continuous extension of NBS since its inception in the 1970s, many children whose life could be saved by earlier diagnoses and treatment are still confronted with diagnostic delays. At the same time, first successful gene therapies are entering the market and personalized genomic medicine develops at fast pace. Oftentimes, its impact on health outcomes critically depends on early diagnoses. Rapidly decreasing costs and turn-around times for genome-wide sequencing would now allow for genomic NBS (gNBS), a major extension of NBS programs by inclusion of disorders undetectable for currently applied NBS technologies. Despite its envisioned benefits emerging from early diagnosis and treatment of early-onset treatable conditions, broad genetic testing in children comes with major ethical challenges. One of such is the definition of ethical criteria for selecting diseases a gNBS program should screen for. This is illustrated by gNBS research studies like the BabySeq project, a U.S. study currently in its second phase that screens for thousands of diseases. BabySeq's criteria for selection of target diseases are broad. Especially controversial from an ethical perspective is the inclusion of actionable adult-onset only conditions in the BabySeq study protocol. The controversy results because this interferes with newborns' future right to decide autonomously whether they want to get tested or not.

Methods
The overall methodology of this talk is that of normative applied ethics and analytic philosophy. The talk consists of three parts: 1) description of the BabySeq case; 2) outline of a strong argument for screening newborns for adult actionable conditions, inspired by reasons BabySeq gave in publications describing their approach; 3) formulation of a counterargument to the argument outlined in part 2. The counterargument is based on two premises: a) the design of gNBS should be in the child's best interest and b) be guided by Kant's Categorical Imperative "So act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means."

Results
BabySeq argues that screening newborns for adult actionable conditions can save their parents' life who might also be affected by the disease (result of part 1). This certainly is in the child's best interest if such screening of newborns is necessary to benefit their parents (result of part 2). Only the problem of such reasoning is that there are other ways to inform parents about own genetic risks. However, these other ways are more expensive. Implementing an adult genomic screening program for all adults for adult actionable conditions in addition to gNBS for childhood-onset only diseases is likely more expensive than screening newborns for adult- and childhood-actionable conditions at once. But economic reasons cannot justify a violation of newborns' future autonomous rights to genetic self-determination. Therefore, screening newborns for adult actionable conditions potentially instrumentalizes them for an economic end (result of part 3).

Conclusions
It is to be recommended that a public health gNBS program does not include screening for adult actionable conditions unless a clear non-economic necessity for such screening is defined.

4.5.3

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Navigating uncertainty in 22q11 deletion syndrome: how healthcare professionals balance hope and realism.

22q11 deletion syndrome (22q11DS) is a rare genetic disorder with variable clinical manifestations affecting multiple organ systems. To understand the challenges faced by healthcare professionals caring for individuals with 22q11DS, we conducted semi-structured interviews with 20 professionals, from different specialties in Canada and Europe, who support children aged 3-15 years with the deletion. The interviews aimed to identify challenges, strategies to assist and guide families, and personal perceptions of family struggles. After reflexive thematic analysis, three themes and several sub-themes were identified, all related to uncertainty. However, this theme took on different meanings: 1. Acknowledging epistemic uncertainty 2. Understanding existential uncertainty 3. Reacting to and coping with uncertainty. Representative and anonymized quotes were extracted from each interview. Participants were aware of the uncertainty in 22q11DS and understood the struggle it creates for families. Their coping experience mainly involved humility and balancing realism and hope when caring for these families. Their sense of duty to serve their patients remained essential. Despite early identification, medical uncertainty remains understudied and deeply entrenched in a static state. Whether reacting to ethical uncertainty in the form of denial and false overconfidence or with doubtfulness, one cannot ignore the strain it places on medical professionals, sometimes limiting their ability to fulfill their duties or leading to constant stress and hesitation. Additionally, in a world where shared decision-making is crucial, facing uncertainty by withholding information could affect the relationship between patients and professionals. Uncertainty in rare diseases is acknowledged, but navigating uncertainty in that context remains a challenge. Our findings highlight the urgent need for increased resources and support for professionals working with families of children with 22q11DS, a rare disease. Greater attention to supporting healthcare professionals through educational initiatives or research on medical uncertainty is critical for improving their skills and managing the undeniable medical ambiguity present.

4.5.4

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Taking the risk. A systematic review of ethical reasons and moral arguments in the clinical use of polygenic risk scores

Question
Debates about the prospective clinical use of polygenic risk scores (PRS) have grown considerably in the last years. The potential benefits of PRS to improve patient care at individual and population level have been extensively underlined. Nonetheless, the clinical use of PRS presents a number of unresolved ethical challenges and normative gaps that hinder their optimal implementation. In our study, we investigate the ethical issues raised in the normative literature about the prospective implementation of PRS in the clinic for the prevention and treatment of common complex diseases.

Methods
We conducted a systematic review of reasons of the normative literature following the method outlined by Sofaer and Stretch (2012). The reporting strategy is based on the PRISMA checklist for systematic reviews.

Results
In total, we have included and thematically analyzed 34 records. The findings have been organized in 3 major themes: (1) "Potential harms" outlines the harms of PRS to individuals and their kin; (2) 'Threats to health equity' considers ethical concerns of social relevance, with a focus on justice issues; (3) 'Towards best practices' collects a series of research priorities and provisional recommendations to be considered for an optimal clinical translation of PRS.

Conclusion
We conclude that the use of PRS in clinical care reinvigorates old debates in matters of health justice. However, open questions regarding best practices in clinical counseling, suggest that the ethical considerations and guidelines developed in monogenic contexts will not be sufficient to face PRS emerging challenges and fill the current "normativity gap".

4.6.1

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Endometriosis in Later Life: An Intersectional Analysis from the Perspective of Epistemic Injustice

This study addresses the underexplored intersection of ageism, sexism and ableism in the context of endometriosis, a chronic inflammatory condition. While discussions about endometriosis typically center on gender inequality during the reproductive age, limited attention has been given to intersectionality and the impact of ageism on affected individuals, despite persistence or reoccurrence of the condition in older age. Thus, older adults with endometriosis may face intersectional discrimination, encountering biases in diagnosis and treatment due to gender, disabilities, and older age. They might experience a special form of injustice, referred to as epistemic injustice, in which persons are wronged in their status as knowers. Concerning this, I use a critical lens combining perspectives of epistemic injustice and intersectionality to create a deeper understanding of such complex forms of injustice and discrimination in healthcare. Through a rigorous analysis of case studies using this combined lens, this study aims to provide insights into the challenges experienced by a diverse group of older adults living with endometriosis, addresses ethical implications by uncovering marginalizing dynamics in healthcare settings, and advances our understanding of discrimination. The aim of this article is to develop a robust analytical approach that systematically explores the multidimensionality of epistemic injustice. It advocates for a holistic healthcare approach, that recognizes the unique needs of individuals with chronic illness at the intersection of ageism, sexism and ableism, contributing to the goal of overcoming marginalization in the context of healthcare.

4.6.2

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Intersectionality as a tool for clinical ethics consultation

Bioethics increasingly recognizes the impact of discriminatory practices, e.g., based on social categories such as race, gender, sexual orientation, or ability, on clinical practices and ethical conflicts. Accordingly, major bioethics associations have stressed that identifying and countering structural discrimination in clinical ethics consultations is a professional obligation of clinical ethics consultants. Yet, it is still unclear how clinical ethics consultants can fulfill this obligation. More specifically, clinical ethics needs both theoretical tools to analyze and practical strategies to address structural discrimination within clinical ethics consultation.

Intersectionality, a concept developed in Black feminist scholarship, is increasingly considered in bioethical theory. It stresses how social structures and practices determine social positions of privilege and disadvantage in multiple, mutually co-constitutive systems of oppression.

Based on a concrete case example, this presentation explicates how intersectionality can contribute to addressing structural discrimination in clinical ethics consultations. To this end, we critically review existing approaches for clinical ethics consultants to address structural racism in clinical ethics consultations and extend them by intersectional considerations. We argue that intersectionality is a suitable tool to address structural discrimination within clinical ethics consultations and is thus suitable to translate anti-discrimination into clinical ethics practice. We show that it can be practically implemented in two complementary ways: 1) as an analytic approach and 2) as a critical practice.

As an analytic approach, intersectionality directs our attention to aspects that are obscured in analyses which are either oblivious to power structures or focus on a singular system of oppression. Intersectionality can thus enable a more profound understanding of an ethical conflict within clinical ethics consultations. In practice, this may be achieved through an *intersectional fact collection* to carve out if structural discrimination plays a role in an ethical conflict, using *counter-storytelling* to allow for a different framing of the ethical conflict from the patient's perspective, a *broadening of ethical frameworks* beyond the four principles proposed by Beauchamp and Childress, as well as *diversifying the composition of clinical ethics committees.*

As a critical practice, intersectionality aims to address power structures and enhance the voice of minoritized patients. This may be achieved through *additional meetings with the patient* before or after the clinical ethics consultation to ensure adequate representation of their perspective, *establish equal shares of speech* and applying *anti-discrimination moderation rules* during the clinical ethics consultation and trying to *unpack potential biases*. Furthermore, *listening and learning sessions* with members of marginalized communities might help to learn about the concrete healthcare needs and barriers of specific communities. Finally, we highlight that supportive institutional structures are necessary for anti-discrimination within clinical ethics consultations to be possible. Author contributions: All authors contributed to the study conceptualization. MF, LB and CH had the initial idea for the paper. MF, LB, AS-G and CH performed the literature search and philosophical elaboration. The original draft of the manuscript was mainly written by MF and CH, LB and AS-G also contributed in writing parts of the manuscript. All authors critically reviewed the line of arguments and revised the manuscript for important intellectual content.

4.6.3

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"Integrated" Empirical Bioethics: Who, What, When?

Introduction

There is an increasing role for integrating empirical and normative analysis within bioethics, with growing numbers of contemporary studies described as "empirical bioethics". However the methods for integration of these epistemologically distinct endeavors and the intended outcomes of studies are reported with variable -degrees of methodological clarity and sometimes inconsistent use of terminology. This scoping review, which is a work in progress, seeks to map out "integrated empirical bioethics" studies and draw out good practice and areas for improving reporting. The review will be completed by summer 2024.

Methods

A literature search was undertaken during early 2024. With the support of a specialist research librarian, we searched CINAHL, Embase, Medline, PsychINFO, Social Science Citation Index and Arts and Humanities Citation Index. Studies have been de-duplicated and resulting records screened against pre-specified inclusion and exclusion criteria. 1535 titles and abstracts were reviewed by both authors. We are currently in the process of reviewing the 221 full text articles.

Anticipated Results

As well as displaying the volume of articles which report "integrated empirical ethics" studies, we will report on the variety of different ways that this is carried out. We will report and analyse author location, subject matter, type of journal and use of empirical bioethics terminology. We will report on the specific methodology used, and the depth with which this is described, focusing on how well the integration of the empirical and normative is achieved. We will also report on the extent to which conclusions are translated into practice and whether the end result of studies are normative conclusions, recommendations for practice, or the implementation of recommendations.

Discussion

Early trends from our title/abstract review are that integrated empirical ethics research is largely focused on clinical and research ethics and originates from a small number of nations within the Global North. There is a paucity of studies in other areas or from the rest of the world. Inconsistent use of terminology makes analysing authors" intentions and aims for what the research seeks to accomplish challenging, particularly regarding normative aspirations.

Summary

This much needed scoping review provides, as far as we are aware, the only full account of published integrative empirical bioethics studies thus far. Much research in this area has focused on a methodological discussion of what empirical ethics is, but pays less attention to the research that is being published under this banner. This review is therefore essential for those new to empirical bioethics, whether they are students or researchers from adjacent disciplines, to be able to understand and confidently enter the field. By presenting these results, we will contribute to ensuring high standards of research and reporting across this heterogeneous and multidisciplinary field.

4.6.4

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Physicians responsibilities in relation to environmental and climatic crises: A critical interpretative synthesis

The environmental and climatic crises have motivated calls for the medical profession to take action by assuming additional responsibilities. These calls to assume responsibilities towards environmental protection and systematically considering the environmental impact on health, greatly vary in their scope and demandingness. Through a critical interpretative synthesis of journal publications, we have mapped the various normative and practical responsibilities and duties attributed or self-attributed to physicians as a professional group. We have also analysed the justifications when these were spelled out. We thereafter have grouped these new professional responsibilities and duties as (i) duties to identify new health risks, (ii) responsibilities to reduce the environmental footprint and implement resource conservation strategies, (iii) responsibilities to prepare the health sector for the upcoming climatic threats, (iv) duties to inform oneself, (v) duties to inform patients, (vi) duties to warn the public and policy-makers, (vii) responsibilities to protect the environment and climate, (viii) duties in relation to children, (ix) responsibilities towards older adults, and (x) responsibilities for future generations. To justify these demands, it was often referred to that physicians (a) are trusted, (b) have special knowledge and skills, (c) are responsible for health issues, (d) are in a unique position to enforce environmental standards in their institutions, and (e) are perceived as important role models. In their totality, these responsibilities go far beyond actions within the traditional patient-physician relationship and demand from physicians to get involved within their institutions, their community, engage with policy-makers and even concern themselves with the health effects of environmental changes on distant others, such as people in other parts of the world and future generations. We present the results of our critical interpretative synthesis and discuss the ethical implications.

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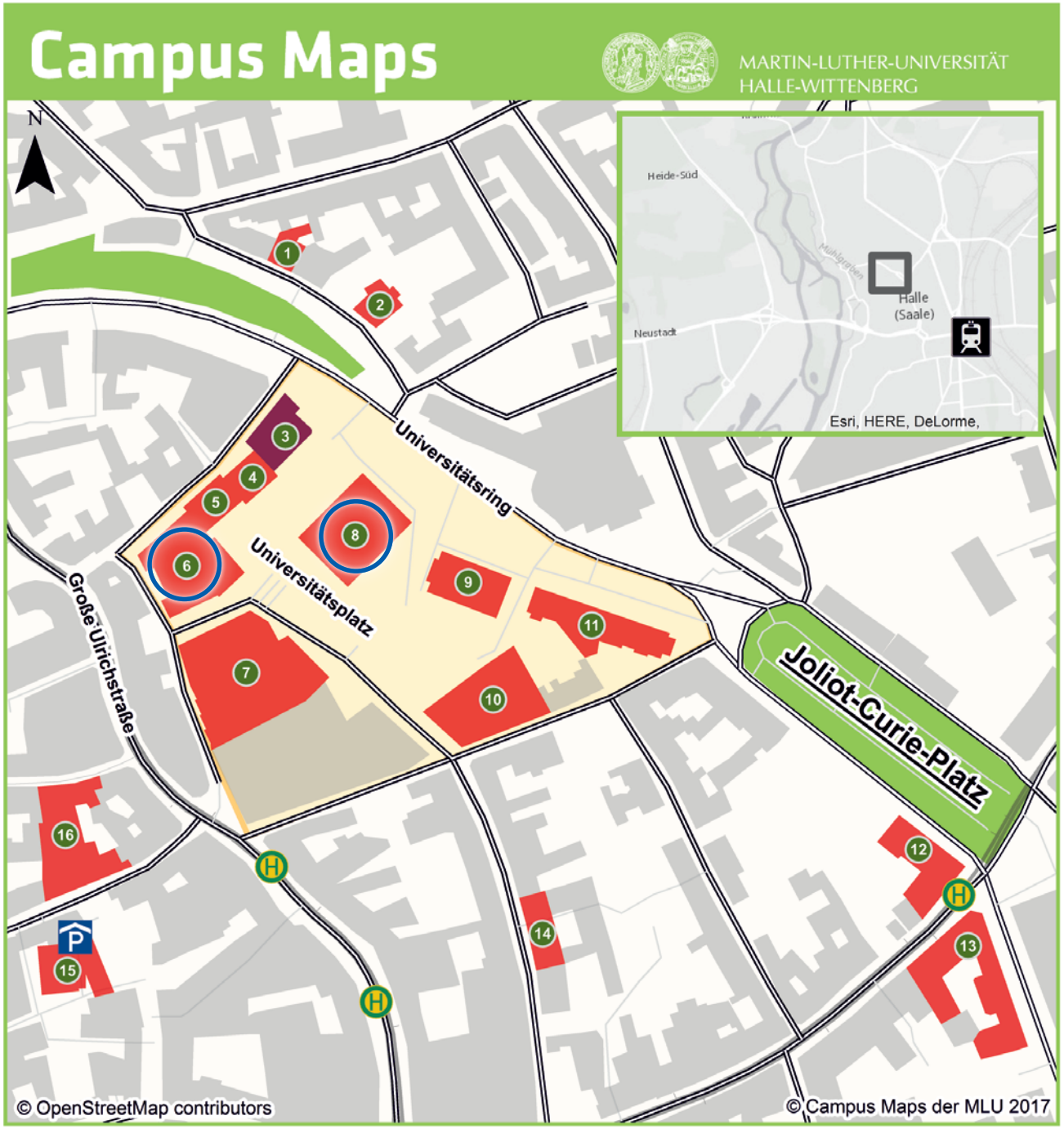

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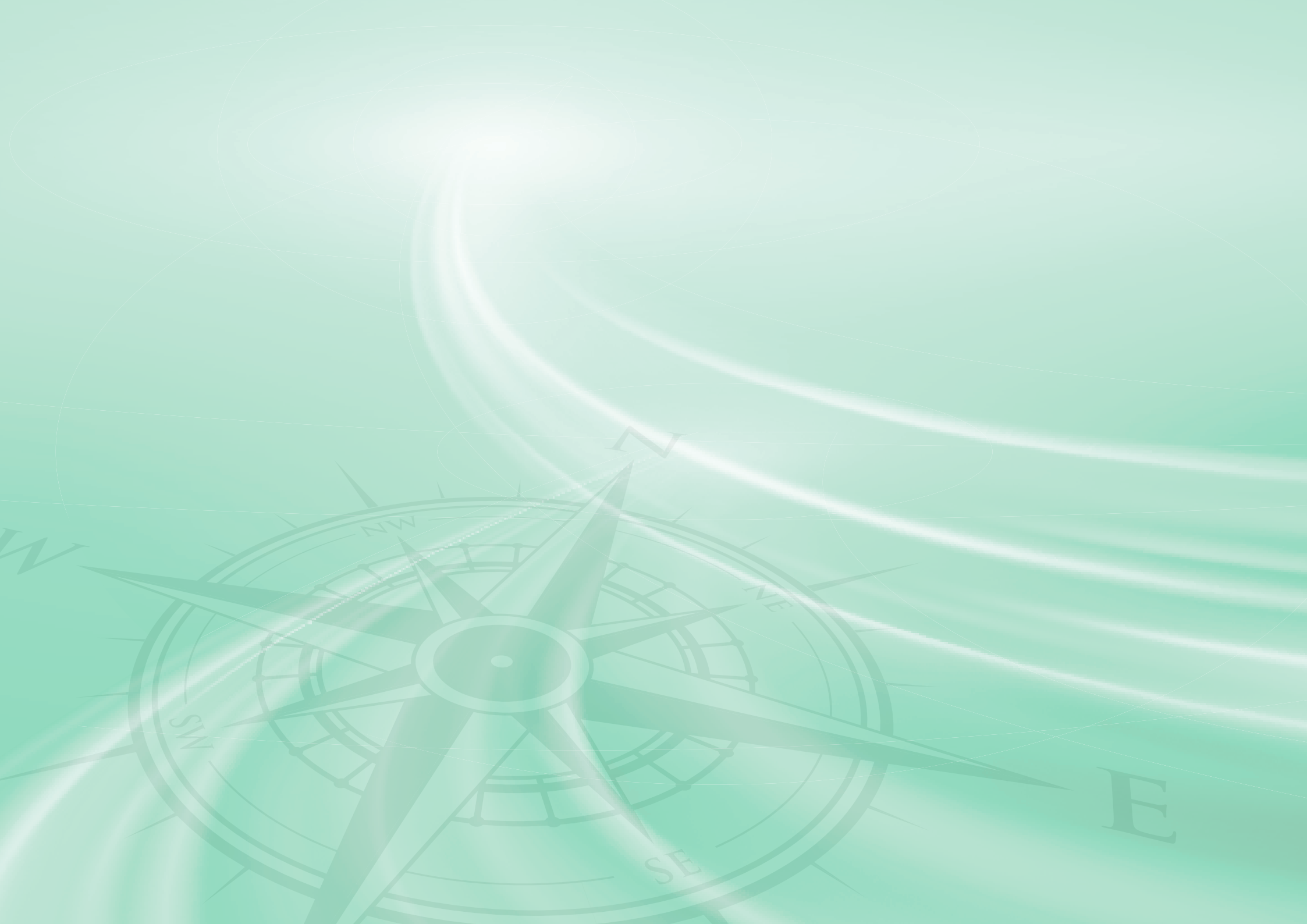
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