



EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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EDITORIAL

EDITORIAL

Dear EACME colleagues and friends,

I hope you had an inspiring conference in Warsaw and that you had fruitful exchanges and opportunities to build collaborations! EACME would like to further foster collaborations and exchanges between its members and initiated the EACME pool for expertise sharing. Interested individuals are therefore invited to sign up for the expertise pool if they would like to be contacted for presenting their research and topics of their expertise at other member institutions (see p. 5 for further information).

In this issue, we would also like to emphasise the “Black and Brown in Bioethics” Initiative, which was launched in the UK by three colleagues to establish research, events, training resources led by people of colour, aiming to promote anti-racism and focus on issues affecting ethnic minorities. The three founders achieved the Paul Schotsmans prize for their research project “Inclusive bioethics: modifying methodology to transform research”, which they also present in this issue.

In addition to this, you will find in this issue a summary about the webinar on Metaverse and its role in mental healthcare, and two PhD thesis summaries on moresprudence and organizational learning on moral issues and on shared decision-making in transgender healthcare. I wish you an enjoyable reading of this newsletter and a great semester start.

Very best wishes,
Caroline Brall

NEWS FROM THE EACME BUREAU

Dear EACME members, colleagues and friends

It is with great pleasure that we write you this 'News from the Bureau', and look back at a really wonderful conference in Warsaw: FACING DISRUPTION. CHALLENGES TO BIOETHICS, HUMAN RIGHTS AND DEMOCRACY. As EACME Bureau, we especially would like to thank Pawel Lukow and his hard-working team to make this conference a truly good and pleasant conference. Thank you for all the efforts and the extra hours you as a team put together in organizing this conference! The atmosphere, as usual during EACME conferences, has been described by others as friendly, informal and welcoming. This created many possibilities to meet both known and new colleagues in the field of Medical Ethics (and beyond). We also would like to thank the four excellent keynotes: David Archard, Rosemarie Bernabe, Barbara Prainsack, and Petra Verdonk. You really contributed to the relevance and urgency of the theme of this year's EACME conference and you challenged us as Medical Ethics community to respond to this in the coming years.

There is more good news from the Bureau: during the General Assembly (always Friday afternoon during the EACME conference), we welcomed two new EACME Board members: Dario Sacchini from the Catholic University of Rome and Manuel Trachsel from the Clinical Ethics Unit from four academic hospitals in Basel.

Furthermore, Jan Schildmann, from the Institute of History and Ethics of Medicine (Halle University Germany), announced the dates and

topic of the new EACME conference next year: TRANSLATING ETHICS INTO HEALTH AND RESEARCH: POTENTIALS AND RISKS. Safe-the-date: Thursday the 12th of September until Saturday the 14th of September 2024.

Finally, please see the information in this EACME Newsletter about a new initiative from EACME: EACME members are invited to register their research areas, if they would like to show and offer their specific professional expertise so that other EACME members can contact them (e.g. for a Webinar, a lecture, joint education, grant writing etc). And vice versa: you as EACME member can have a look at the register if you are searching for a EACME colleague with specific expertise. Within this Newsletter, Kristine Bærøe from Bergen University (and also Oslo University) explains how it works.

Wishing you a good autumn,

Bert Molewijk (Secretary General of EACME),

on behalf of the EACME Bureau
Ruth, Federico, Pawel and Angelique)

EXPERTISE SHARING

Would you agree to be contacted by EACME colleagues to present your research to students and/or colleagues at other EACME institutions?

Many EACME members are engaged in teaching and organizing seminars on medical ethics. Some of us also teach areas of medical ethics in which we might not be experts. At the same time, chances are good that someone in another EACME institution is working specifically on matters you and your students want to learn more about.

The EACME board/bureau wants to create a pool of people who are willing to contribute online to courses or meetings on medical ethics across Europe.

The idea is that you can be invited by another EACME member to present a specific paper you have authored yourself, or a theme you are particularly keen on presenting and discussing.

The format of the presentation is basically the presenter's choice; it can be shorter or longer (for example 20 minutes or an afternoon session), involving just the presentation with a few Q&As or more time for discussion and interaction with the audience. Presenters control this themselves by describing what they wish to talk about, and how they prefer to do so, on the list administered by EACME and available on the website in the EACME members section (accessible only through your member login).

This is a great opportunity for institutions and members to consolidate the EACME network, but also for:

- ▶ researchers to reach out with their work beyond their own networks and build new cooperations (also beyond teaching, for joint research projects)
- ▶ students to learn from the experts and engage directly with authors presented in their curriculum
- ▶ course coordinators to get to know colleagues across country and institution borders

This is how it works:

We invite everyone affiliated with an EACME institution to register their name, their thematic field of expertise and specific papers they would like to talk about via sending an email to Angelique: a.heijnen@maastrichtuniversity.nl

She will put the information in a table located on EACME member's space on the web page. By doing so, they consent to being approached by other EACME members with an invitation to give a talk online to a class or in a seminar.

EACME members who would like to have a topic discussed from different angles or simply wish to spice up their courses with a 'meet the author' session, can register for access to the list of names and themes, and find colleagues in other institutions or European countries who are willing to contribute to courses or meetings.

The contributions are free. The arrangement is expected to stimulate a culture of informal and easily accessible exchange: people contribute with their expertise to enrich courses and meetings outside their own institution and invite

others to do the same in their own working place. If an event is open to others outside of your institution, we invite the organisers to announce it through the EACME News.

If you like to share your expertise:

- Send an email to Executive Board Secretary Angelique Heijnen (a.heijnen@maastrichtuniversity.nl) with contact information and theme(s) you would like to present/discuss with other EACME members, and Angelique will put your information on the list

If you like to benefit from the expertise of other EACME members:

- Login in on EACME's member webpage to access the list of names and themes and then you can contact people with the relevant expertise directly

Introducing “Black and Brown in Bioethics”

We are Harleen Kaur Johal, Matimba Swana, and Kumeri Bandara, and we are co-founders of “Black and Brown in Bioethics (BBB)”. We launched BBB following the realisation that there are no regular events in UK bioethics that are led by people of colour or focus on issues affecting ethnic minorities. Our mission is to achieve racial equity within the UK bioethics community by conducting research, creating network, organising events, and providing training resources that promote anti-racism and accelerate the well-being, education, and health of all. Below, we give you a taste of a selection of initiatives we are currently working on. You can find more details about our work at <https://blackbrownbioethics.blogs.bristol.ac.uk/>, and email us with any suggestions or comments at <https://blackbrownbioethics.blogs.bristol.ac.uk/contact-us/>.

Research projects

[Inclusive bioethics methodology research project](#)

As co-founders of BBB, we are honoured to receive this year's Paul Schotsmans prize for our research project “Inclusive bioethics: modifying methodology to transform research”. Kumeri is leading this project, which maps out the kinds of discrimination and bias inherent in mainstream research methods in the UK context, and calls for critical engagement with and rethinking of these methods. In doing so, we also explore what makes for exclusionary and inclusionary research methods. The project has three components: a literature review, an autoethnography, and a Delphi study. The conference paper abstract for which we won the Paul Schotsmans prize is on the

autoethnography component, and the prize money will be used to organise and conduct the Delphi study next year. The paper is based on our experiences as researchers from minoritised backgrounds; reflections on planning, developing, and executing empirical research projects as part of our respective PhDs; and involvement in other research projects. As such, we draw from a collective data set of 100 interviews we carried out in the UK in 2022 and 2023 for our PhDs, corollary research experiences, and associated methods. We outline the structural and individual biases inherent in developing research questions, recruiting participants, selecting consent processes, advertising projects, interviewing, and coding data, among other methodological steps. We contextualise our discussion within existing critiques that appear in decolonial and feminist literature to show how the uncritical use of mainstream methods in bioethics research can exclude and undermine the experiences and voices of minoritised and underprivileged communities. We also show how such exclusion deprives bioethics research of data that are truly representative of the diverse communities around us. In reviewing literature, we consolidate related ideas scattered across existing work on the topic. Finally, we emphasise the need for more focused research on discrimination and biases in mainstream research methods and discuss what researchers can do to overcome these issues in planning, developing, and implementing their projects.

We are delighted to have already shared components of this project at this year's Oxford Global Health and Bioethics Conference (OGHBC) and the Institute of Medical Ethics (IME) conference.

Being Black and Brown in Bioethics (BBBB) study

Harleen is leading BBBB—a qualitative study into the experiences of postgraduate researchers in different racial groups—which is supported by generous funding from the IME. There is growing evidence of racial inequity in academia and healthcare. Bioethics Postgraduate Researchers (PGRs) are students working at the intersection of these two systems, yet the experiences of ethnic minority PGRs working in bioethics are comparatively underexplored. This study aims to understand the experiences of PGRs from ethnic minority backgrounds working in UK bioethics, by investigating the extent to which they are affected by (in)direct racism at individual and/or systemic levels. The study also aims to identify possible strategies for reducing racial inequity in bioethics. The research team is also made up of Matimba, Kumeri, Dr Zuzana Deans (University of Bristol), Dr Mehrunisha Suleman (University of Oxford), and Nako Abdullah (University of Bristol).

Events

Webinar series

Matimba is leading the organisation of a series of webinars, starting with one on “Bioethics and global health: in search of common ground”, which was on 5 September 2023 with Caesar Atuire, Sharon Kaur, Isabella Aboderin, and Rishita Nandagiri (session chair). This webinar focused specifically on the divide—but also the similarities—between the ‘Global North’ and ‘Global South’, and aimed to identify areas of learning and convergence that should become the focus of future collaboration and development. The webinar had 168 registrants. You can watch a recording of the event here: <https://www.youtube.com/watch?v=MIng57O-FMQ>

The next webinar will be on “Insights from industry” on 1 November 2023 with Evelyn (Eve) Kamau (Thermo Fisher Scientific), Niyoshi Shah (Quicksand Design Studio), Srushhti Trivedi (Amaris Consulting) and Arianna Manzini (DeepMind, session chair). This webinar will focus on digital health from an industry perspective with the aim to evaluate and discuss: (1) the past, present and future digital health landscape, (2) digital health inequalities, (3) digital health inclusion strategies, and (4) the reason digital inequalities and inclusion matter in healthcare. If you would like to attend, please register [online](https://blackbrownbioethics.blogs.bristol.ac.uk/event/insights-from-industry-inclusionary-digital-health/) <https://blackbrownbioethics.blogs.bristol.ac.uk/event/insights-from-industry-inclusionary-digital-health/>

Panel at the Postgraduate Bioethics Conference (PGBC) 2023

We are grateful to have collaborated with the chairs of this year’s PGBC—Emma Nance and Jamie Webb—who kindly gave us time in the programme to host a plenary session entitled “Disrupting bioethics as a postgraduate: advocacy and activism” on 12 June 2023. The panel created an opportunity to learn from the reflections of experienced researchers on how to channel our energy and work most effectively towards a more equitable future. This tied in with this year’s conference theme: “Futures of bioethics”. Emma and Jamie chose this theme to reflect on past and present pressing issues in bioethics as well as to use this conference as an opportunity to horizon-scan, with a view towards anticipating how the bioethics field could, and should, expand in the future.

Many thanks to our panellists Professor Patricia Kingori (University of Oxford), Dr Agomoni-Ganguli Mitra (University of Edinburgh), and Dr Ayesha Ahmad (St George’s, University of London) for sharing their thoughtful and candid reflections on how they have engaged with

activism during their careers, and to Kumeri for steering the conversation.

Black and Brown in Bioethics (BBB) 2024 conference

Matimba is leading the organisation of our first BBB conference, “Engaging diversity in bioethics theory and practice” on 9 April 2024 in Bristol, UK. BBB chose the conference theme to counter the lack of active recognition and consideration given to meaningful engagement of diverse voices and experiences in the bioethics field. The conference will follow a hybrid format, with both online and in-person delegates, and it will consist of four plenary sessions and two keynote presentations. Many academics we look up to have already accepted our invitation to speak. During the conference, there will be ample opportunity for discussion and networking between established members of the bioethics community and postgraduate researchers. Save-the-dates will be sent out in the coming months but if you would like to subscribe to our calendar and receive these updates automatically, you can do so here: <https://blackbrownbioethics.blogs.bristol.ac.uk/events/>.

Training and resources

Training workshop in collaboration with the UK Clinical Ethics Network (UKCEN) conference 2023

Harleen led a collaboration with UKCEN, and specifically Professor Richard Huxtable (University of Bristol, Chair of UKCEN), in co-organising the annual pre-conference training workshop for members of Clinical Ethics Support Services (CESS) on 22 June 2023. UK CESS are widely considered to have three key functions: case consultation, policy, and education. In this workshop, we used two case studies to consider how racism—at individual and structural levels—may present to CESS through their various

functions. The case discussions were facilitated by people with lived experience, researchers, and advocates—all of whom have experience of engaging with social justice issues in healthcare—and discussion around these cases explored the role CESS could play in addressing inequity in clinical practice. We have received positive feedback from attendees, and would like to thank Kumeri, Dr Louise Austin (Cardiff University, University Hospital of Wales Clinical Ethics Committee), Dr Aisha Davies (Black Mothers Matter), Ms Rakeb Yoseph (Bristol Medical School), and Dr Jo Hartland (Bristol Medical School) for helping plan and facilitate this workshop.

Power and privilege podcast

We are organising a limited series of podcasts exploring “Power and privilege in academia”. Each podcast is led by one of the BBB co-founders, and is in conversation with two academics working in bioethics. The themes we cover in this series are navigating research culture within the US and UK, inclusivity in publishing, anti-racism within higher education establishments, disrupting hierarchies to

improve education, activism and advocacy as postgraduates, and challenges faced by postgraduate researchers in bioethics. We are grateful to be supported by Oxford Podcasts, and we’re on track to release this podcast series in Autumn 2023.

Inclusive bioethics video series

Complementary to the “Inclusive bioethics: modifying methodology to transform research” project, Kumeri is also leading the creation of a video series to act as a free training resource (open access) for postgraduates, early career researchers, and other interested parties. The aim of this initiative is to provide tools to develop and implement bioethics research projects with inclusive design principles that include the diverse demographics and lived experiences of marginalised groups, and relevant and appropriate theories and concepts. The videos will feature expertise contributed by experienced researchers working with different marginalised and underserved communities across the globe. The production of the videos is funded by the IME’s Postgraduate Student Committee (PSC). We are aiming to release the videos in 2024.

Webinar Summary: The Metaverse: A Role to Play in Mental Healthcare?

Oriane Pierrès, IBME, University of Zurich

On April 25th, 2023, the Forum for Global Health Ethics hosted [a webinar entitled “The Metaverse: A Role to Play in Mental Healthcare?”](#). The forum is an outreach initiative at the University of

Zurich, gathering stakeholders with various backgrounds to discuss critically ethical issues in global health.

The webinar provided an overview of the state of the metaverse and related digital applications in mental healthcare, its potential, and its risks. The necessity to regulate the field was also discussed. Three speakers were invited, each representing a different field of expertise. Thomas Douglas is a philosopher and works as a Professor of Applied Philosophy at the University of Oxford. Victoria Lush has a background in computer science and is a post-doctoral researcher at Aston University. Katitza Rodríguez is a lawyer working as a policy director at the Electronic Frontier Foundation. Tania Manríquez Roa and Nikola Biller-Andorno from the University of Zurich in Switzerland hosted the session.

The metaverse: a response to a shortage in mental healthcare support?

Victoria Lush started the webinar by discussing the metaverse's potential in mental healthcare, drawing on her knowledge and the work of Ulysse Bernander, Christopher Buckingham, and Jomar Alcantara. She highlighted the global significance of mental health issues, leading to disability, reduced life expectancy, and high costs for healthcare systems. Despite the importance of the conditions, there is a shortage of mental health professionals and inadequate public funding. In the United Kingdom (UK), the demand for mental health support surpasses the available resources, resulting in extended waiting times (at least six weeks). Other organizations also provide support. For instance, mental healthcare charities gather information for self-support, but users often feel overloaded with information. Additionally, self-assessment and self-management tools online and numerous mental health-related apps provide "on-the-go" therapy advice. However, those online tools are often unregulated and thus lack supervision with regard to their validity and efficiency.

Digital technologies using augmented and virtual realities (AR / VR) offer solutions. Lush emphasized their capacity to provide intermediate support to those with limited access to practitioners. Diagnostic and self-help tools enable continuous mental health assessment, reducing the need for immediate professional intervention. Generally, technologies could help scale up the mental health offer. However, Lush noted that access to technologies can also be challenging and thus may not reach everyone. The researcher also explained that AR and VR technologies can make cognitive-behavioral therapy (CBT) and training more engaging and novel than filling out paper-based questionnaires or online forms. Treatments can also become more personalized and on-demand. Virtual social and peer support networks may feel safer for people with social anxiety than attending an in-person event. Emotional virtual companions could also tackle isolation. Nevertheless, Lush cautioned that reliance on virtual companions may hinder real-world social interaction.

How to mitigate the risks in the metaverse?

Katitza Rodríguez highlighted the increasing interest of companies to use AR / VR in their business activities. While acknowledging that the technology is not yet advanced, Rodríguez emphasized the need to consider the potential risks of data misuse. For instance, she raised concerns about advertisers gaining access to brain data to not only understand consumer interests but also manipulate desires and preferences directly. Meanwhile, sensors are improving every year, and users are eager to wear these devices.

Currently, wearable devices already record sensitive data. For example, wearable devices collect biometric data and health indicators. According to Rodríguez, AR / VR technologies are expected to elevate data collection for

immersion (e.g., exposure therapy) and monitoring purposes (e.g., to send help alerts). These devices measure not only conscious activities but also unconscious mental processes, necessitating informed consent. Public awareness should be increased since individuals may unknowingly reveal personal information.

According to Rodríguez, the legal debate and existing international human rights frameworks have focused on conscious and voluntary reactions to data privacy and protection issues. Meanwhile, newer artificial intelligence (AI) technologies collect unconscious mental processes and thus create more complex situations for data protection. Regulations like GDPR focus on the use and the sharing of personal data, whereas mental privacy is a more extensive matter, as it is more deeply connected to individuals. This raises questions about accessing files containing inner thoughts when, for example, law enforcement requests the medical records of a suspect.

Furthermore, the private sector may not be subject to existing norms or be aware of standard procedures to address ethical concerns. Rodríguez argued that fostering competition and a decentralized approach to development could benefit individuals by giving them more choices, allowing companies to compete based on superior privacy protection. Moreover, Lush underlined the need to involve practitioners in self-assessment technology development as well as to conduct risk assessments. Another avenue to explore is restricting the collection of data and its repurposing; however, this requires a capacity to encrypt data safely.

The need for a right to mental integrity

Thomas Douglas argued that individuals should have a right to mental integrity, similar to bodily

integrity. Informed consent should be required for any interference with our minds, even in non-physical interventions. This right is based on the principle of self-ownership, where everyone owns their body and mind. It also aligns with the moral intuition that practices such as forcing medication or non-consensual use of hypnotic techniques are wrong. In the context of virtual therapy, this right becomes particularly significant as interventions may come from non-medical practitioners, such as tech companies. Unlike medical staff, technicians are not used to follow ethical norms and healthcare-related regulations. Similarly, Rodríguez highlighted that companies are increasingly using sensors to monitor attention levels or identify individuals. She also explained that big tech companies have economic incentives to repurpose data to maximize profits. At the same time, hackers may target brain-computer interfaces and thus steal personal thoughts and memory. The webinar's discussion underlined the importance of regulating virtual therapies, especially as Douglas noted that psychological harm is currently less regulated than physical harm.

When could the right to mental integrity be violated?

Douglas identified two situations where non-consensual interventions could violate mental integrity. Firstly, there are interventions that alter thoughts or attitudes without providing reasons. For example, reducing arachnophobia by explaining the low risks associated with spiders would not infringe mental integrity since it is based on logic. However, exposing someone to subliminal images of attractive people with spiders to decrease their fear would violate their right to mental integrity. Secondly, interventions that modify thoughts or attitudes in ways that are difficult to resist are problematic. For instance, if a therapist alters the virtual reality environment of an enthusiast to include spiders,

it infringes mental integrity as it lacks reasoning and restricts the individual's ability to reject the intervention.

Furthermore, the question arises as to whether nudging can interfere with the right to mental integrity, even if it encourages users to engage with privacy policies, for example. Douglas and Rodríguez expressed concerns about nudging potentially infringing on the right to mental integrity. Douglas emphasized the importance of considering the effects on individuals' thoughts and attitudes, suggesting that some nudges may undermine autonomy and invalidate consent if resistance is difficult.

In the webinar discussion, Douglas also highlighted the need to grant a right to mental integrity as a fundamental moral principle. Nevertheless, from a legal perspective, there is a need to narrow the scope of the right to mental integrity. This entails focusing on specific technological interventions to ensure enforceability.

Conclusion and future research

In sum, Lush highlighted that AR / VR technologies open opportunities not only to reduce the supply-demand gap, but also to improve the quality of services. At the same time, there are concerns that these technologies may not live up to their potential as people may not access technologies, or they could exacerbate mental health issues by disconnecting people from one another. In addition, Rodríguez underlined that the increasing collection of sensitive and personal data raises concerns about data misuse and theft.

Regulations governing the use of AR/VR technologies in mental healthcare need to be established and revised, mainly due to the entry of companies into this field. The discussion

suggested mandating informed consent, raising public awareness, fostering competition and a decentralized approach to technological development, granting and protecting a right to mental integrity, involving medical practitioners, and conducting risk assessments.

Additionally, Lush reckoned that exceptions will always be necessary to deliver services to everyone depending on their needs. For example, people with visual impairments could benefit more from therapy with audio immersion rather than visual virtual reality. Furthermore, not everyone has access to AR / VR technologies, a smartphone, or the internet. It is, therefore, vital to legally guarantee the provision of alternative offline services.

Finally, based on the comments from all speakers, future research in this field will likely focus on developing specific regulations tailored to different contexts and creating effective strategies for their implementation. Another critical aspect to consider, mostly highlighted in Lush's presentation and answers, is how to leverage AR/VR technologies to ensure their benefits are accessible to all, without exacerbating existing inequalities. It is crucial to avoid a scenario where technology becomes the sole solution for individuals without access to medical professionals. In addition to the valuable insights shared during the webinar, it is worth considering the importance of incorporating user perspectives in the design of technologies for mental healthcare. The inclusion of user experiences, particularly from individuals with impairments, can offer unique expertise that is sometimes overlooked. There is a necessity to ensure that virtual environments are flexible enough so that they can be navigated by people with impairments. For instance, AR/VR technologies can include captions to facilitate communication or color contrast and magnification options to make the environment

more visible (see Dick, 2021). User input also has the potential to enhance the acceptability and effectiveness of these technologies, ultimately leading to more impactful solutions for mental healthcare.

Further Readings

- Dick, E. (2021, June 1st) [Current and Potential Uses of AR/VR for Equity and Inclusion](#). Information Technology and Innovation Foundation.
- Lighthart, S., Ienca, M., Meynen, G., Molnar-Gabor, F., Andorno, R., Bublitz, C., . . . Kellmeyer, P. (2023). Minding Rights: Mapping Ethical and Legal Foundations of ‘Neurorights’. *Cambridge Quarterly of Healthcare Ethics*, 1-21.
- Lush, V., Buckingham, C., Edwards, S., & Bernardet, U. (2020). [Towards Accessible Mental Healthcare through Augmented Reality and Self-Assessment Tools](#). *International Journal of Online and Biomedical Engineering (iJOE)*, 16(04), pp. 33–42.
- Gloeckler, S. and Biller-Andorno, N. (2023) [Mental health services in the metaverse: potential and concerns](#). *Swiss Medical Weekly*. Vol. 153 No. 4

- Rodriguez, K. and Mir, R. (2022, December 24th). [Pivotal Year for the Metaverse and Extended Reality: 2022 in Review](#). Electronic Frontier Foundation.

Acknowledgements

The Metaverse webinar was conceived of and organized by Tania Manríquez Roa, Nikola Biller-Andorno, Dominik Bolliger, and Sophie Gloeckler, all from the University of Zürich in Switzerland. The Webinar was hosted by the Forum for Global Health Ethics in association with a project supported by the Commonwealth Fund: Mental Healthcare in the Metaverse: Exploring the Ethical and Regulatory Landscape.

Upcoming Webinars

In 2023, the Forum for Global Health Ethics will host two more webinars: one on triage and justice, and one on drug pricing. The dates of the webinars will be announced on our website (<https://www.ibme.uzh.ch/en/Biomedical-Ethics/who-collaborating-centre/Forum-for-Global-Health-Ethics.html>) and via email (to receive information about our webinars, send us an email to globalhealthethics@ibme.uzh.ch).

PhD Thesis Summary

Moresprudence and organizational learning on moral issues

Henriëtte Bout, Maastricht University

Henriëtte Bout’s thesis ‘Moresprudence and organizational learning on moral issues’ discusses the presence of moral issues within organizations and the importance of addressing

them appropriately in order to learn as an organisation. This study employs the 4I framework (Intuiting, Interpreting, Integrating, and Institutionalizing) of Srossan et al (1999) to

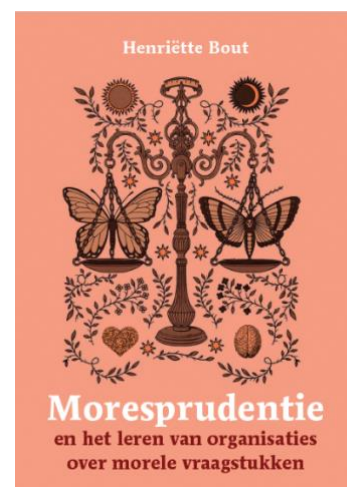
describe organizational learning about moral issues.

Handling moral issues effectively is crucial for relieving moral stress of employees and maintaining an organization's reputation. Key findings indicate that learning about moral issues often occurs within the work environment, through discussions and critical evaluations of moral arguments. The process of "moral matching," where moral arguments align, is essential at various organizational levels.

The thesis explores the role of moral deliberation and "moresprudence" in organizational learning. Moresprudence refers to documents capturing the outcomes of moral deliberations, serving as a knowledge repository for organizations. The thesis investigates how different forms of moresprudence can contribute to sustained learning about moral issues within organizations. Hindering and supporting factors are identified and described in the process of transferring moral knowledge within organisations. The thesis also examines the potential role of ethicists in guiding moral deliberations and moresprudence development.

The research methodology includes a combination of qualitative approaches: literature review, multiple case studies, in-depth interviews with ethicists, and a Delphi survey among ten Dutch organisations experienced in developing moresprudence . The cases studied

involve two different practices: organizations engaged in animal testing and the municipality of Amsterdam. The study highlights the multifaceted nature of moresprudence and suggests that it can contribute to sustained organizational learning about moral issues by providing insights, guiding frameworks, and contributing to the organizational memory.



Henriëtte Bout - Moresprudentie en het leren van organisaties over morele vraagstukken ©2023
ISBN/EAN: 978-90-8980-162-3, NUR: 801
Download: see: www.conscience.nl

PhD Thesis Summary

Shared decision-making in transgender healthcare: Ethical and conceptual challenges and the co-creation of an ethics support tool

Karl Gerritse, Center of Expertise on Gender Dysphoria and the Department of Ethics, Law, & Humanities, Amsterdam UMC, location VUmc

This thesis has two central aims.

First, to gain insight into the moral and conceptual landscape of gender-affirming medical care (GAMC) for transgender (trans*)

adults, specifically concerning shared) decision-making (SDM). Second, to (2) co-create an ethics support tool to foster (a joint reflection on) good SDM and aid healthcare professionals (HCPs) and trans* clients in recognizing and handling its concomitant ethical challenges. To these ends, we addressed the following research questions:

- Which ethical challenges do HCPs working in a multidisciplinary GAMC center in the Netherlands experience? (Chapter 2)
- What are the ethical challenges and norms concerning SDM of adult trans* clients who received GAMC in the Netherlands? (Chapter 3)
- What are the ethical challenges and norms concerning SDM of HCPs providing GAMC to adult trans* clients in the Netherlands? (Chapter 4)
- What are the conceptual assumptions regarding decision-making and client autonomy in two care models for GAMC, and what are their key ethical challenges? (Chapter 5)
- How do HCPs in GAMC “enact” Gender Dysphoria in daily practice, and what normative assumptions concerning GD do these enactments reflect? (Chapter 6)
- What ethics support tool can foster (a joint deliberation and reflection about) good SDM in

GAMC and help stakeholders to recognize and handle its concomitant ethical challenges? (Chapter 7)

Chapter 1 introduced the research aims against the background of GAMC, SDM, and the need for theme- and practice-specific CES. Trans* ¹ individuals have gender identities or expressions that differ from their sex assigned at birth. Increasingly, trans* people seek GAMC: interventions such as feminizing (de-masculinizing) and masculinizing (de-feminizing) hormones and/or surgeries. GAMC may improve the quality of life of trans* people by affirming and expressing their experienced gender, thereby alleviating what is currently classified as “Gender Incongruence (GI)” or “Gender Dysphoria (GD).” Since the late 1970s, stakeholders have worked toward developing standards of care and establishing the guiding ethical principles of GAMC, such as physical health, mental well-being, self-actualization, and safety. Still, both HCPs and trans* clients appear to experience ethical challenges related to the question: What is good decision-making?

Increasingly, stakeholders in GAMC call for more shared decision-making (SDM). SDM emphasizes the importance of personalized care, shared ownership in decision-making, and responsibility for choosing (or deferring) treatment. SDM is becoming ever more prominent in healthcare (policy) and is

¹ Transgender (trans*) is an umbrella term referring to various gender identities, roles, and expressions

differing from those (normatively expected from) one’s sex assigned at birth.

considered the ideal decisional model, especially for so-called “preference-sensitive decisions,” i.e., decisions where more than one reasonable treatment option is available. GAMC is a preference-sensitive care practice par excellence. Indeed, given the ever-expanding availability of GAMC options and the diversity of clients’ needs and values regarding their medical transition, the growing appeal for SDM in GAMC is not surprising. Yet, SDM is normatively and conceptually ambiguous, raising the question of what SDM actually is and how it should be attuned to the specifics of GAMC.

These questions on SDM are becoming more pressing in the context of increasing referrals to and waiting lists for GAMC. The increasing number of those seeking GAMC entails that more people are (and will be) confronted with such questions. Additionally, some see the “gatekeeper role” of mental health professionals (MHPs) in decision-making as one of the causes of the growing waiting lists and hence dispute it. Moreover, questions about SDM arise in a polarizing social and academic discourse on gender diversity in general and (decision-making in) GAMC in particular: the voices arguing for radical self-determination or, conversely, the restriction or criminalization of GAMC are getting louder. The above makes the question of what constitutes good SDM in GAMC not only contested and uncertain but also highly urgent. Clinical ethics support CES aims to help stakeholders deal with ethical issues in clinical practice. Thereby, it seeks to improve moral competencies, cooperation, and quality of care. CES may aid trans* clients and HCPs in recognizing and handling ethical challenges about SDM but also help establish a reference for what good SDM in GAMC should entail. Increasingly, CES is offered in GAMC through ethics consultations and Moral Case Deliberation (MCD). CES may also be offered, for example, through the co-creation of theme- and practice-specific CES tools. It could prove fruitful to co-

create an ethics support tool focused on the theme of SDM and the practice of GAMC. This thesis examines how HCPs and trans* clients in GAMC may be supported in fostering good SDM and dealing with related ethical challenges. It investigates what type of ethics support tool suits these aims best.

The development of this tool necessitates a thorough understanding of stakeholders’ needs and the moral, conceptual, and contextual landscape of SDM in GAMC: What ethical challenges (concerning decision-making) are stakeholders confronted with when providing or receiving GAMC? How do these challenges relate to care models and clinical guidelines? What is the impact of stakeholders’ conceptual and normative assumptions regarding GI/GD on (the provision of) GAMC? Research into these questions is sparse yet vital to inform the co-creation of a theme and practice-sensitive CES tool and to further the dialogue on what good SDM in GAMC entails. We grapple with these questions in the first two parts of this thesis. Part A describes the ethical challenges and norms of HCPs (Chapters 2, 4) and trans* clients (Chapter 3). Part B elucidates the conceptual and normative assumptions regarding decision-making and client autonomy (Chapter 5) and investigates how HCPs “enact” GD in GAMC (Chapter 6). Informed by the previous chapters, Part C describes the co-creation of GenderJourney, a visual ethics support tool (Chapter 7). In keeping with a pragmatic-hermeneutic and dialogical take on CES, we seek to sensitize SDM (“theory”) to the field of GAMC (“practice”) and vice versa, with the ultimate aim of improving current decision-making practices in GAMC.

Part A: Mapping stakeholders’ ethical challenges and norms

Chapter 2 describes a focused ethnography of the ethical challenges of HCPs working in a

specialized multidisciplinary GAMC center in the Netherlands. Over seven months, we observed multidisciplinary team meetings and individual consultations. Furthermore, we analyzed transcripts and reports from MCD sessions. Through a thematic analysis, we found that professionals faced ethical challenges in (1) determining the circumstances under which trans* individuals should be rendered ineligible for treatment; (2) shaping the content of treatment in the absence of a firm evidence base and the context of “non-traditional” treatment requests; (3) dealing with the multidisciplinary nature and sequential order of various treatments; (4) establishing the strictness of and possible variations from clinical guidelines; (5) assessing the “presence” and “authenticity” of GI/GD; and finally (6) SDM. Ethical challenges concerning SDM proved especially pressing and urgent. Indeed, HCPs often described balancing an experienced duty to non-maleficence and a commitment to respecting clients’ self-determination. In practice, this balancing act led to diverse moral and ethical questions, such as: Should we start treatment when a client does not oversee or cope with the consequences of treatment? Who should decide whether a “non-traditional” treatment request is permissible? What are the moral boundaries of the treatment options?

Chapter 3 and **Chapter 4** aim to descriptively elucidate the decisional ethical challenges and norms of trans* clients and HCPs, respectively. We conducted 10 semi-structured interviews with adult Dutch trans* people who received GAMC and 11 semi-structured interviews with HCPs working in two distinct Dutch GAMC settings for adults (academic and non-academic). We analyzed our interview data using thematic analysis. Many (especially trans*) respondents were more inclined to speak about what good or right decision-making ought (not) to be instead of expressing ethical uncertainty or

doubt. Therefore, we decided to identify both ethical challenges and ethical norms. Furthermore, in our analysis, we differentiated between respondents’ explicitly expressed and implicit ethical challenges and norms we ascertained indirectly from the transcripts. Finally, we elucidated the context in which the latter emerged.

For trans* clients, we identified the following overarching ethical norms and questions: (1) Clients ought to be in the lead, but what should this entail? (2) Harm should be prevented, but who should be responsible? (3) The decision-making process ought to be attuned to the client, but what should this attunement involve? We italicized the questions above as we saw that clients’ diverse decisional values frequently corresponded to divergent ethical norms, of which the practical and ethical consequences regularly varied. They thus require iterative interpretation and deliberation. We also described how clients’ ethical challenges and norms often pertain to the specific context of (power differences within) the client-clinician relationship. Clients also related their ethical norms concerning SDM to implicit and explicit notions about what GI/GD is (not): more *laissez-faire* in the case of “natural variation” and more paternalistic in the case of a “mental disorder.” We also found a strong effect of time, partly related to the transition process itself, i.e., clients’ values regarding their treatment and good decision-making often shifted.

HCPs’ overarching ethical challenges were: (1) How should we divide and define our decisional roles and bounds? For example, when should we delay or withhold treatment? (2) How should we negotiate decision-making as a (multidisciplinary) team? For example, what is my responsibility in multidisciplinary decision-making? (3) How should we navigate various decision-making temporalities? For instance, what should be the impact of potential future consequences on current decision-making? We

found that these ethical challenges were embedded in a context characterized by epistemic and normative uncertainties regarding (1) GAMC's guidelines, evidence, and outcomes and (2) the boundaries and assessment of GI/GD. Overarchingly, we found that HCPs often implicitly adopted different decision-making models. Similarly, clients appeared to arrive in the consultation room with various needs, fears, and dynamic normative views regarding decision-making but did not regularly share these with their HCPs. Together, these findings illustrated how decision-making in GAMC is best understood as an ongoing dynamic process, constantly—yet often implicitly—negotiated among various stakeholders and distributed across places and times. In our view, the diversity, complexity, and temporally contingent character of stakeholders' decisional ethical norms underscore the need to diversify and explicitly attune decision-making to the dyad, intervention, and context at stake. Therefore, we argue that the first step toward good decision-making is to make the content and context of the specific decision and stakeholders' corresponding ethical norms and values more explicit to allow joint dialogue and deliberation. Given its pervasive impact, this endeavor requires attentiveness to how the decisional context (such as the utilized care model) may cultivate or hamper the latter.

Part B: Elucidating conceptual and normative assumptions

Chapter 5 explores clinical ethical challenges concerning decision-making in light of two different care models used in GAMC: the Standards of Care 7 (SoC7) and the Informed Consent Model (ICM). The SoC7 hold that MHPs are best prepared to diagnose GI/GD and assess clients' eligibility for GAMC given their specific training and because GAMC is often intensive and (partially) irreversible. Contrarily, the ICM

emphasizes clients' self-determination and minimizes the role of HCPs in decision-making to provide information and obtain informed consent. This Chapter aims to clarify the conceptual and normative assumptions regarding decision-making and client autonomy in these care models and to ultimately better understand key ethical challenges in practice.

Our conceptual analysis shows how SoC7 recommends both assessorial and supportive tasks for MHPs. These dual tasks indicate a tension between weak paternalistic and deliberative decisional assumptions and conflicting conceptions of client autonomy. We describe how this tension contributes to a role conflict on the part of HCPs, which may be met with apprehension, mistrust, and selective information exchange on the part of clients. We conclude that this dynamic may impinge on the client-clinician relationship, undermine decisional deliberation, and, ultimately, the realization of good care.

At first glance, the ICM appears to bypass this ethical predicament. However, our analysis illustrates that in the ICM, collaborative decision-making and attuning to clients' individual decisional needs could be hampered by a legalistic and narrow interpretation of informed consent and client autonomy. Our analysis also shows that the conceptual and normative understanding of informed consent in (the various local care models that fall under the rubric of) the ICM is often ambiguous. This ambiguity may lead to questions about what should be considered sufficiently informed consent in practice.

Based on our analysis, we suggest that foregrounding one normative model for decision-making is no moral panacea. We conclude that the first steps toward good SDM in GAMC are acknowledging and discussing its inherent normative and moral dimensions.

The prior studies showed how stakeholders' and guidelines' normative convictions concerning SDM in GAMC often hang together with conceptual assumptions regarding GI/GD. This relation is also evident in the history of GAMC: paternalistic assessment and decision-making processes were often justified as the object of care was conceptualized as a (mental) disorder. Against the background of the recent depsychopathologization of GI/GD, **Chapter 6** examines how the object of GD is shaped in current clinical practice and what norms regarding GD and GAMC this reflects. To this end, we draw from material semiotics, which posits that material and immaterial objects, such as GD, are not static but enacted by human and non-human actors and practices. Objects become (ontologically) different and multiple depending on how a given constellation of actors and practices engage with them. In this Chapter, we aimed to clarify how GD is enacted in daily practice by looking at how HCPs and clinical guidelines 'order' it, i.e., how they seek to get a grip on GD. We analyzed (1) 16 interviews with MHPs and relevant excerpts from (2) SoC7, and (3) the Diagnostic and Statistical Manual for Mental Disorders, version 5. Through a thematic analysis, we identified four ways in which HCPs and clinical texts 'order' GD: (1) treating GD as gender (diversity), (2) isolating GD from (other) mental health conditions, (3) gauging the persistence of GD by 'doing' the future, and (4) creating continuity in GD by narrating the past. We illustrate how HCPs and clinical texts move and slip between multiple modes of ordering GD that co-exist, depend on, and conflict with one another. We also draw attention to how these different modes of ordering GD orient toward specific notions of good (decision-making in) GAMC. Our findings provide an empirical foundation to inform normative debates concerning the latter.

PART C: Developing an ethics support tool

Chapter 7 describes the development process of "GenderJourney," an ethics support tool for the consultation room to foster (reflection on) good SDM in GAMC and support stakeholders in handling concomitant ethical challenges. The GenderJourney focuses on the client-clinician relationship and is less problem-driven and cognitive/analytical than other ethics support tools. Theoretically, we based this participatory project on a dialogical take on empirical ethics, which aims to draw normative conclusions based on dialogue with stakeholders in practice. We included trans* clients and MHPs throughout the study in four homogenous and two heterogenous co-creation workshops. During the workshops, we (1) established participants' needs; (2) reached a consensus on the aims, content, and design; (3) developed and tested different iterations; and (4) presented the final version of the tool. The GenderJourney consists of three parts: (A) elucidating the (development of the) client's care request and corresponding decision-making processes and moments; (B) fostering a dialogue between clients and HCPs about expected/preferred decisional roles and collaboration through active verbs (e.g., support, inform, question); (C) stimulating evaluation, and identifying and handling SDM-related ethical questions and challenges; We arrived at these steps as participants expressed that good SDM in GAMC is attuned within the dyad to the person and intervention at stake. Participants stressed the critical importance of good (i.e., open and honest) client-clinician communication and collaboration. They also expressed the need to discuss more explicitly (expectations and ideals concerning) decisional roles about specific decisions/interventions. Moreover, respondents indicated that ethical challenges relating to SDM should be made more explicit and explored. We conclude that an iterative and open dialogue on what good SDM entails for these stakeholders at

that in this context is an integral part of fostering good SDM. We argue, furthermore, that concomitant ethical challenges and dissensus ought to be taken seriously and made more explicit as they indicate the values and norms at stake and thus provide critical input for this dialogue.

In the Discussion (**Chapter 8**) we reflect on our findings and discuss three central points of discussion regarding transgender care, shared decision-making and ethics support, respectively. We conclude these sections with implications for practice and research.

The first section focuses on transgender care in the light of shared decision-making. Here we take a closer look at the ways HCPs' (perceived) decision-making responsibilities are complicated by uncertainties concerning GI/GD, particularly the epistemic inaccessibility of GI/GD and the inherent unpredictability of the effects of "personally transformative" treatment. We argue that HCPs' experienced duty to do no harm to trans* people should be weighed against the possible harms this very endeavor entails for the client-clinician decision-making process and, consequently, (the possibility of) realizing good care. Relatedly, we question whether "regret" ought to be prevented at all costs. In other words: we question "the logic of prevention" and a consequentialist interpretation of decision-making in GAMC. The above does not imply, however, that HCPs have no role in preventing harm. This raises the normative question of what the responsibility of HCPs and trans* clients should be with regard to non-maleficence. We believe that a first step is to identify and jointly explore this question by making the possible harms explicit and deliberating on their implications for good SDM.

The second section focuses on SDM in light of GAMC. Here, we describe how our empirical findings and theoretical framework may inform the ambiguous normative underpinnings of SDM.

We argue that good SDM cannot be determined by applying a set of a priori universal SDM-related values such as "self-determination" or "protection," but should be established by stakeholders in practice, time and again. We argue that such a take on good SDM does more justice to stakeholders' diverse and dynamic values and norms, but also the specific contextual characteristics of GAMC. We explain how this approach to SDM dovetails with pragmatic-hermeneutic clinical ethics. Philosophical pragmatism and hermeneutics hold that our understanding and appreciation of the world are inextricably linked to our perspectives and presuppositions, and that (moral) learning comes about in exchanging them with others. However, our empirical findings illustrate that the possibility and willingness of stakeholders to engage in such an exchange is not self-evident. As such, they raise questions about the feasibility of a hermeneutic dialogue and the democratic attitude assumed by pragmatism.

In the third section, we reflect on pragmatic-hermeneutic CES and CES tools based on our experiences with the development of GenderJourney. We stress the importance of CES as a means of establishing a constructive and investigative dialogue in the current context of polarization of normative positions concerning GAMC. The current debate on GAMC has the tendency to solidify normative presuppositions and narrow the scope for dialogue about what good SDM and GAMC entails, both in the consultation room and beyond. A pragmatic-hermeneutic approach to CES—through its focus on recognizing normative presuppositions and stimulating moral reflection—may be conducive to dialogue about good SDM and a more collaborative approach to concomitant ethical challenges. We also highlight some critical questions and challenges relating to the normativity of a hermeneutic-pragmatic approach to CES, namely: (1) How does it deal

with the resistance and/or inability of some stakeholders to adopt a dialogical or democratic attitude? (2) To what extent does it do justice to the impact of power differentials on the possibility of accounting for both loud and dim voices in moral deliberation? (3) What should be its role vis-à-vis institutional and/or structural barriers to good SDM and, more broadly, good care?

In conclusion, this thesis shows that SDM in GAMC is characterized by ontological ambiguities, epistemic uncertainties and normative contestations. Our empirical findings and a pragmatic-hermeneutical approach to clinical ethics emphasize that good SDM in GAMC necessitates various renditions of, an openness toward, and dialogue about what good SDM may entail for these stakeholders concerning this intervention at that moment and in this context. Ongoing deliberation on what good SDM should entail is vital. Not only in the consultation room—where norms and values pertaining to decision-making are varied, dynamic, (ostensibly) contradictory, and often implicit—but also within institutions and society at large. This thesis offers insight and support to those in clinical practice and provides a basis for future research on SDM and CES in GAMC. Its findings could also be relevant for those in care practices that, like GAMC, are characterized by inherent moral and normative dimensions. Finally, this

thesis is relevant to those developing, providing and researching CES and CES tools, both in and outside GAMC. We hope that the findings and tool presented in this thesis provide a foothold for informational frictions and ongoing, critical-constructive dialogues toward better SDM in GAMC and beyond. Moving towards European Convergence in Classical Individual Patients' Rights

Can the New Individual Patients' Rights to Information under Article 6(3) of Directive 2011/24/EU contribute?

Shared decision-making in transgender healthcare



Karl Gerritse

Book review

Dr Jean Martin, Ancien membre de la Commission nationale suisse d'éthique

Alice Canabate

L'écologie et la narration du pire (Récits et avènements en tensions)

Paris : Editons Utopia, 2021

Alice Canabate, socio-anthropologue et historienne de l'université Paris-Descartes, pose dans cet ouvrage très bien informé et structuré

un regard aiguisé sur la crise, l'anthropocène, la collapsologie – sans qu'elle soit collapsologue. Une exposition-explicitation dense d'où nous en sommes. Incertitudes : « La crise sanitaire covid a vu la bataille des 'mondes d'après'. Cette profusion est un gage de vitalité démocratique et d'engagement de la société civile mais contient également un risque fort d'éparpillement. Tribunes, appels et manifestes se sont multipliés qui ont tenté de constituer une voix commune. »

Effondrement ? « Il y a un effondrement lent et tragique de la capacité critique, de l'honnêteté et de la modestie, de nos capacités de réexamen. » L'auteure discute les émotions liées à la crise écologique (solastalgie, éco-anxiété - p 87-93). Nous devons gérer, dit-elle, une situation de

franchissements de seuils critiques, de ruptures, qui s'alimentent mutuellement pour frapper de plein fouet les générations montantes. Soulignant l'importance de développer de nouveaux récits et des scénarios, ainsi que le fait l'Institut des futurs souhaitables, « école de la réinvention ».

Dans l'épilogue : « Nous avons sans doute à refuser de vivre en redoutant d'être demain, comme si le monde nous était extérieur, inaccessible (...) Le monde est création perpétuelle, refus de rassasiement (italiques de l'auteure) comme le disait Mansur Al-Hallaj, mystique persan du IXe siècle ».

Forschung mit Smartphone-apps

Die Ethikkommission an der Medizinischen Fakultät der LMU München und das Institut für Ethik, Geschichte und Theorie der Medizin der LMU München laden zu einer wissenschaftlichen Veranstaltung ein, zum Thema:

Forschung mit Smartphone-Apps: Ethische, technische und rechtliche Implikationen für die Begutachtung durch Forschungsethikkommissionen an Medizinischen Fakultäten am 19.10.2023, 14:00 -18:00 Uhr in der Anatomische Anstalt der LMU, Kleiner Hörsaal, Pettenkoferstraße 11.

In dieser Veranstaltung sollen die ethischen, technischen und rechtlichen Implikationen der Forschung mit Smartphone-Apps in den Blick genommen werden.

Mobile Gesundheitstechnologien wie Gesundheitsapps auf Smartphones und Wearables (z.B. Smartwatches) bieten viele Möglichkeiten für die Versorgung von Patienten und die Prävention von Krankheiten. Die Anwendungsmöglichkeiten reichen von relativ einfachen Schritt- und Kalorienzählern bis hin zu Geräten, die ein komplexes Monitoring von Krankheitssymptomen oder alltäglichen Handlungsweisen erlauben. Werden mobile Gesundheitstechnologien zur Erreichung von Gesundheitszielen eingesetzt, ist es geboten, sie wissenschaftlich zu überprüfen, das heißt systematisch ihre Wirkung zu beforschen, Standards für ihre Anwendung zu beschreiben

und die damit einhergehenden Risiken zu identifizieren. Doch worauf müssen Antragsteller

und Mitglieder von Ethikkommissionen achten, wenn mit Smartphone-Apps oder Wearables geforscht wird? Welche Risiken gehen mit der Forschung einher und wie können sie minimiert und angemessen gehandhabt werden? Welche Anforderungen sind an den Datenschutz zu stellen, wenn sensible Gesundheitsdaten digital übermittelt werden? Welche rechtlichen Regelungen müssen von Forschenden in jedem Fall eingehalten werden?

Durch Expertenvorträge aus der Informatik (Prof. Dr. Albrecht Schmidt), der Public Health-Ethik (Prof. Dr. Verina Wild) und dem Recht (Prof. Dr. Ulrich Gassner) wollen wir Orientierung geben, welche Herausforderungen bestehen und

welcher Umgang damit ethisch geboten ist. In der Diskussion unter Beteiligung von Mitgliedern und Nutzenden der Forschungsethikkommission (Prof. Dr. Randolph Penning, Prof. Dr. Frank Padberg) an der Medizinischen Fakultät der LMU möchten wir die ethische Urteilsbildung für konkrete Anwendungsszenarien unterstützen und aufzeigen, in Bezug auf welche ethischen Anforderungen bisher (kein) Konsens besteht.

Weitere Informationen und Anmeldung bis 12.10.2023: <https://www.egt.med.uni-muenchen.de/aktuelles/veranstaltungen/wissenschaftliches-symposium/index.html>

SURVEY FUNCTIONING ETHICS COMMITTEES

Dear Ethics Committee,

In 1994, the Ethics Committees were legally established in Belgium. In this decision it is determined what functions are to be performed by these Committees, their composition and general functioning.

In 1994 the tasks were described as follows:

- 1° a guiding and advisory function with regard to the ethical aspects of hospital care;
- 2° a supporting function in decisions on individual cases regarding ethics;
- 3° an advisory function with regard to all protocols regarding experiments on humans.

In 2000, '2°' was annulled by the Court of Arbitration given the governmental structure and the distribution of powers in healthcare in Belgium, the Court held that it did not fall within the powers of the federal legislator.

Within the doctoral work of Mrs. Audrey Van Scharen on Ethics Committees in Belgium, the Ethics Committee of the UZ Brussels wants to research the official establishment of an 'Ethics Consulting Service' whose task is 'a supporting function in decisions on individual ethics cases' to research. In addition, Ms. Van Scharen will examine the desirability of a clearer legal framework for these Ethics Committees.

Your insights and contributions are very valuable. The questionnaire below contains 19 questions. It takes approximately 20 minutes to complete, but might take longer if more comments are added. We value every input, very much!

Link to the questionnaire:

https://vub.fra1.qualtrics.com/jfe/form/SV_0qEPgLEu2uU6nAy

The questionnaire is completed anonymously via Qualtrics. However, it is possible that if you provide further explanation of a question and context, recognition may occur. If you provide your contact details at the end of the questionnaire to participate in a focus group, this survey is no longer anonymous. When processing your data, we respect the regulations regarding the protection of personal data and treat your data with the utmost care and confidentiality.

We sincerely appreciate your time,

Audrey Van Scharen

PhD Candidate
Manager Ethics and Research UZ Brussel
President Medical Device Framework Board
Vice President to the Medical Ethics Committee
VUB – UZ Brussel
Vice President to the Ethics Committee on
Healthcare UZ Brussels

Guest Professor
Faculty of Health and Pharmacy
Department GERO

Also on behalf of the promoters Prof Pieter Cornu
and Prof Michel Deneyer

Call for abstracts

ICCEC & CBS Montreal 2024 October 19th 2023

The Call for Proposals has been published for the Joint Meeting of the International Conference for Clinical Ethics & Consultation (ICCEC) and the Canadian Bioethics Society (CBS), scheduled for May 29-31, 2024 in Montreal, Canada.

The call for proposals will be open from September 15 to November 15, 2023. In line with the conference's main theme "Partnering with patients and communities," we are inviting proposals that investigate and question how all aspects of ethics (clinical ethics, research ethics, policy in health and healthcare, bioethics) consider patient and community engagement. Students are encouraged to submit their work as dedicated sessions are reserved for student participants. Bursaries will be made available for trainees from countries with developing economies, allocated randomly amongst the proposal with the highest reviewer scores.

Two types of proposals can be submitted: workshops and abstracts.

Proposals topics:

- Artificial intelligence and technology
- Clinical ethics in practice
- Education
- Emerging issues, Diversity, Disparity and Inclusion
- End-of-life, palliative care, assistance in dying
- Health Humanities, Law, Philosophy, Religion and Social Science
- International Development and Cooperation
- Patient engagement in healthcare ethics (clinical, research, policy)
- Pediatric ethics
- Research ethics

Corresponding authors whose proposals are selected for inclusion in the conference will be informed at the beginning of February, 2024. All speakers must register for the conference and present at the conference venue in Montreal. Further details about submission and further information about the conference can be found at

<https://event.fourwaves.com/iccec2024/pages>

Fondation Brocher

2025 Call for Proposals | Residencies & Workshops

View [here](#) for more information.

DEADLINE NEXT NEWSLETTER

The deadline for the third edition of 2023 is:

November 15, 2023

An opportunity to promote your event, to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any ideas for contributions for the upcoming edition?

Please get in touch and do not hesitate to contact our editor Caroline Brall: caroline.brall@unibe.ch

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