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An interdisciplinary and bilingual newsletter about advances in health ethics theory and practice

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**PRAGMATIC
HEALTH ETHICS
RESEARCH UNIT**



IRCM

Institut de recherches
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Volume: 15, Issue: 1

News from the Pragmatic Health Ethics Research Unit

New publication!

This article presents quantitative results from a mixed-methods survey of autistic adults and parents/guardians of autistic people in Canada, France, Germany, Italy, and the USA:

[Autism service preferences of parents/guardians and autistic adults in five countries.](#)

M. Ariel Cascio, Eric Racine. *Autism Res.* 2022 Jan 18.

Monthly profile

Suzanne Metselaar, Ph.D.

Dr. Suzanne Metselaar is Assistant Professor of Ethics and Medical Philosophy at the

PhD in Philosophy. Her research focuses on elderly, palliative, and end-of-life care. Central to many of her projects is the question of how health care professionals can be supported in dealing with ethical challenges in health care practice. She additionally writes on the philosophical principles of a clinical ethics founded in philosophical pragmatism, dialogical ethics, and hermeneutics.



As a clinical ethicist, she provides ethics support at several institutions. She is Vice Chair of the Medical Ethics Committee of Amsterdam UMC and trains health care professionals in various ways to provide clinical ethics support, such as Moral Case Deliberation and CURA, both nationally and internationally. Dr. Metselaar is also Vice Coordinator of the 2-year Master's programme Philosophy, Bioethics & Health, and teaches bioethics in different academic curricula.

A participatory approach to clinical ethics support

In my research, I take a participatory approach to clinical ethics support (CES): I proceed from the idea that normative conclusions can best be reached through a dialogical process that includes the people who have 'lived experience' of the ethical issues at hand. This goes for case reflections, but also for the development, implementation, and evaluation of CES instruments.

The 'CURA project', which I have been leading over the last four years, revolves around the question 'How can caregivers that provide palliative care be supported in dealing with their moral dilemmas?'. A relatively easy-to-use CES instrument called CURA was co-created together with various stakeholders on the basis of a participatory development study design, and is now also used in other domains of health care.

The benefits of a participatory approach to the development of a CES instrument – or any health care intervention – is that the wishes and needs of end users and other stakeholders be taken into account throughout the development process. This promotes the feasibility and acceptability of the intervention. It also promotes co-ownership and responsibility among the intended users, and thus supports implementation. Furthermore, the development optimally benefits from the (experiential) knowledge that stakeholders bring with them. For instance, a distinctive element of CURA is the incorporation of reflection on the emotions that may come with the experience of a moral dilemma, particularly as stakeholders involved have insisted that this is important. We are currently studying the implementation and effectivity of CURA in various health care settings.

Selected publications

Metselaar, S., Van Schaik, M.V., Widdershoven, G., Pasman, H.R. CURA: An Ethics Support

Van Schaik, M.V., Pasman, H.R., Widdershoven, G., Molewijk, B., Metselaar, S. CURA—An Ethics Support Instrument for Nurses in Palliative Care. Feasibility and First Perceived Outcomes. HEC Forum (2021). <https://doi.org/10.1007/s10730-021-09456-6>

Metselaar, S., Widdershoven, G., Porz, R. and Molewijk, B. Evaluating Clinical Ethics Support: A Participatory Approach. Bioethics 2017, 31: 258-266. <https://doi.org/10.1111/bioe.12348>

Website

<https://research.vumc.nl/en/persons/suzanne-metselaar>

Events and announcements

The Montreal Health Ethics Conference Series

The Montreal Health Ethics Conference Series is an annual series of bilingual conferences / webinars that aims to bring together clinicians, academics, patients, politicians, public figures, students, and community members to think about and discuss issues in health ethics. The series' objective, supported by many academic institutions located in Montreal, is to promote interdisciplinary reflection as well as foster new ways of thought that better assemble the larger public.

2022 THEME: Information and Health: Still the crux of the matter?

After decades of promoting patient rights and organizational transparency, is information still the crux of the matter in healthcare? There are many barriers to an optimal flow of information: the opacity of information on the functioning of the health system, the overabundance of contradictory information on mental and physical health, the emergence of telehealth platforms, and the role of the media in providing accurate information on health in times of pandemic. The Montreal Health Ethics Conference Series will call on various stakeholders from political, scientific, and government circles, as well as patients to determine whether information and its accessibility are still a fundamental health issue. Together, we will try to understand why and for whom this issue persists and discuss the possible solutions and promising practices. [Click here](#) for the conference series calendar.

Conférences de Montréal en éthique de la santé

Jeudis - 12 h
Mode hybride | Gratuit
110, avenue des Pins Ouest, Montréal H2W 1R7

ZOOM EVENTBRITE
YOUTUBE INFOS SÉRIE

L'information en santé : Toujours le nerf de la guerre?

<p>Janvier 27 Président: Valérie Bourde, chef du bureau Science et santé, ingénierie sociale, Philippe Marquis, éditeur, Le Pressat. Dr André Veilleux, directeur, Unité de recherche en éthique pragmatique de la santé, IRCM. Animateur: Dr Abbeus Simon Senghar, chercheur postdoctoral, IRCM.</p> <p>Gestion de l'information en santé en contexte de pandémie</p>	<p>Avril 21 Animateur: Isabelle, professeure adjointe, IRICM. Les données cliniques: 'en vie réelle': Pourquoi est-ce à la fois si nécessaire, difficile et risqué?</p>	<p>Octobre 13 Dr Daniel Contandopoulos, professor and acting director of Institute on Aging and Lifelong Health, University of Toronto. Une analyse politique des barrières à l'accès aux données pour la recherche en santé.</p>
<p>Février 17 Mme Geneviève Piché, spécialiste, droits en santé, Réseau Marché-Action.</p> <p>Les aspects légaux de l'information en santé</p>	<p>Mai 20 (vendredi) Président: Chanté Assante, professeure adjointe. Dr Emily Lévesque-Fortin, directrice de la clinique de recherche post-COVID-19. Dr Amir Elhadad, chercheur en éthique pragmatique, Centre Hospitalier Pierre-LeGardeur. Jérôme Marier-Sénéchal, Association québécoise de la médecine de l'urgence. Animateur: Ariane Gauthier, étudiante au PhD, IRICM.</p> <p>Méthodes d'audit, soins de qualité et information en santé</p>	<p>Novembre 10 Dr Robert Young, professor and director, Center for Health, Behavior and Society, Johns Hopkins University. What is brain death? The imperative to communicate honestly and transparently with the public.</p>
<p>Mars 17 Discussion-débat entre Dr Eric Racine et Dr Luc Béliveau, président, directeur général, RECSM.</p> <p>Innovation et information en santé</p>	<p>Juin 9 Dr Marie-Pascale Poirier, professeure titulaire, IRICM. Marie-Josée Cloutier, professeure postdoctorale, Océan Pacific, cabinet-partenaire.</p> <p>Le partenariat de soins et de services au niveau clinique: un soutien émotif, informationnel et éducatif grâce à l'accompagnement par les pairs</p>	<p>Décembre 1 PANELISTES: À confirmer. ANIMATEUR: Dr Abbeus Simon Senghar.</p> <p>Retour sur la Série de conférences 2022</p>
<p>Avril 1 (vendredi) Président: Dr Christiane Aguilera, directrice de l'information de contrôle du dosage, Institut de Santé Publique, Université de Montréal. Dr Eric Racine, directeur, Centre de recherche en éthique pragmatique de la santé, IRICM. Dr Geneviève Piché, spécialiste, droits en santé, Réseau Marché-Action. Dr Luc Béliveau, président, directeur général, RECSM. Dr Marie-Pascale Poirier, professeure titulaire, IRICM. Animateur: Dr Eric Racine, directeur, Unité de recherche en éthique pragmatique de la santé, IRICM.</p> <p>Sport, information et santé mentale</p>	<p>Septembre 15 Dr René Gagnaire, professeur et directeur, Laboratoire de Santé publique, éducation et promotion de santé, Université Sorbonne Paris Nord.</p> <p>Les prises de risque d'une pédagogie de l'éducation thérapeutique de patients</p>	<p>Série présentée par l'Unité de recherche en éthique pragmatique de la santé.</p> <p>En collaboration avec: Le CHU Sainte-Justine et le Bureau de l'éthique de la faculté de médecine de l'Université de Montréal.</p> <p>Ethique clinique IRICM</p> <p>CHU Sainte-Justine Université de Montréal</p>

Les aspects légaux de l'information en santé

[Me Geneviève Piché](#), avocate spécialiste, droits en santé, Ménard Martin Avocats

17 février 2022 – 12h PM à 1h PM (EST)

Pour vous inscrire : [Cliquez ici](#)

[Call for proposals: Add Questions or a Survey Experiment to the ENHANCE-Panel Study \(Wave 4 in Autumn 2022\)](#)

Faculty of Management, Economics and Social Sciences, University of Cologne

This call encourages colleagues to propose modules with a maximum duration of 90 seconds (i.e., survey items/scales, vignette experiments, or suggestions for interventions) for the fourth and last wave. For all questions and submission of the application, please contact Dr. Sebastian Sattler, sebastian.sattler@uni-bielefeld.de.

Deadline for submissions: March 15th, 2022.

Acceptance notifications will be sent out by April 15th, 2022.

For more details: [Click here](#).

[Call for proposals – ASBH 24th Annual Conference: “Reimagining and Claiming the Role of Public Bioethics and Health Humanities”](#)

October 26-29, 2022 – American Society for Bioethics + Humanities

Presenters are invited to use lessons learned from the COVID-19 pandemic to reimagine and claim the public role of bioethics and the health humanities, reflect on different types of interconnections and engagement with the public, and together chart new courses forward.

Deadline for submission: March 4, 2022 – 6PM (CT)

For more details or to submit a proposal: [Click here](#).

[Call for applications: Peer reviewers for ASBH 24th Annual Conference](#)

October 26-29, 2022 – American Society for Bioethics + Humanities

The 2022 Program Committee invites new and returning peer reviewers to help select proposals for presentation at ASBH's Annual Conference. Review the expectations and eligibility information [here](#), and complete the volunteer form to indicate your willingness to serve and your areas of interest.

2021 Peer reviewers are invited to fill out the ["2021 Returning Reviewers" form](#). New reviewers and previous reviewers that did not serve in 2021 are invited fill out the ["New Reviewers" form](#).

Deadline for application: February 7, 2022 – 11:59 PM (CST)

[Appel de candidatures : Agent\(e\) de planification, de programmation et de recherche - Comité Éthique Recherche](#)

CIUSSS du Nord-de-l'Île-de-Montréal

Sous l'autorité du Directeur Adjoint de la DQEPE, le titulaire du poste est membre d'une équipe multidisciplinaire de professionnels dédiés au Comité d'éthique de la recherche. Le lieu de l'emploi est au CHSLD Notre-Dame (formule hybride télétravail).

Date limite pour appliquer : 3 février 2022

[Appel aux inscriptions: 5^e Journée d'éthique clinique \(virtuelle\)](#)

8 avril 2022, de 8h15 à 12h30 – Bureau de l'Éthique Clinique, Université de Montréal

Pour cette 5^e JEC, le comité scientifique a le plaisir de collaborer avec le Comité sur l'équité, la diversité et l'inclusion (EDI) de la Faculté de Médecine de l'Université de Montréal, afin d'explorer « La richesse de la diversité en éthique clinique ».

Pour vous inscrire : [Cliquez ici](#).

Pour plus d'informations : [Cliquez ici](#).

[Appel de candidatures : Siéger au Comité sur l'éthique et l'intégrité scientifique du FRQNT](#)

Fonds de recherche du Québec – Nature et technologies

Ce Comité fournit des avis au conseil d'administration en matière d'éthique de la recherche et d'intégrité scientifique dans les domaines des sciences naturelles, des sciences mathématiques et du génie. Envoyer lettre de motivation et CV au Comité d'évaluation des candidatures à l'adresse ethique.frq@frq.gouv.qc.ca en indiquant comme objet « Candidature – FRQNT ».

Date limite pour appliquer : 15 février 2022.

Pour plus d'informations : [Cliquez ici](#).

[Appel de candidatures : Siéger au Comité sur l'éthique et l'intégrité scientifique du FRQSC](#)

Fonds de recherche du Québec – Société et culture

Ce Comité fournit des avis au conseil d'administration en matière d'éthique de la recherche et d'intégrité scientifique dans les domaines des sciences sociales et humaines, de l'éducation, de la gestion, des arts et des lettres. Envoyer lettre de motivation et CV au Comité d'évaluation des candidatures à l'adresse ethique.frq@frq.gouv.qc.ca en indiquant comme objet « Candidature – FRQSC ».

Date limite pour appliquer : 15 février 2022.

Pour plus d'informations : [Cliquez ici](#).

[Call for applications: 1st permanent chair for the Department of Health Humanities & Bioethics](#)

School of Medicine and Dentistry (SMD), University of Rochester

They seek an innovative, energetic, and visionary leader who can position the department as a national leader in health humanities and bioethics.

To apply: Send a cover letter and curriculum vitae to: Jeffrey M. Lyness, MD Senior Associate Dean for Academic Affairs - University of Rochester School of Medicine & Dentistry

Jeffrey.Lyness@urmc.rochester.edu

For more details or to apply: [Click here](#).

[Call for applications: Assistant professor without tenure, Department of Pediatrics, Division of Bioethics & Palliative Care](#)

University of Washington School of Medicine

This position will have the opportunity to engage in research and scholarship in fields that intersect with bioethics and palliative care, such as law, medicine, decision-science,

To apply: [Click here.](#)

For more details: [Click here.](#)

Literature

Interdisciplinary foundations of health ethics

[How to identify priority questions for bioethics research.](#)

Millum J. *Am J Bioeth.* 2022 Jan;22(1):17-18.

[Mind the gap please: Ethical considerations in the transition of virtual consultations from crisis to usual care.](#)

Moerenhout T. *J Med Ethics.* 2022 Jan;48(1):36-37.

[One health ethics](#)

Capps B. *Bioethics.* 2021 Dec 12.

[The normative implications of recent empirical neuroethics research on moral intuitions.](#)

Dubljević, V. *Neuroethics.* 2021 Apr 6;14:449–457

[Les principes d'équité et d'utilité dans l'allocation des ressources limitées en situation de pandémie](#)

Saint-Arnaud J, Mullins G, Ringuette L. *Can J Bioeth.* 2021 Jan 8;4(1):1-14

Methodologies and practices in health ethics

[Stakeholder perspectives on returning nonactionable apolipoprotein L1 \(APOL1\) genetic results to African American research participants.](#)

West KM, Cavanaugh KL, Blacksher E, Fullerton SM, Umeukeje EM, Young B, Burke W. *J Empir Res Hum Res Ethics.* 2022 Apr;17(1-2):4-14

[Human research ethics committee experiences and views about children's participation in research: Results from the MESSI study.](#)

Taplin S, Chalmers J, Brown J, Moore T, Graham A, McArthur M. *J Empir Res Hum Res Ethics.* 2022 Apr;17(1-2):70-83

[Honesty and transparency, indispensable to the clinical mission - Part III: How leaders can prevent burnout, foster wellness and recovery, and instill resilience.](#)

Brenner MJ, Hickson GB, Boothman RC, Rushton CH, Bradford CR. *Otolaryngol Clin North Am.* 2022 Feb;55(1):83-103. doi: 10.1016/j.otc.2021.08.004.

[Using public deliberation to set priorities: The case of COVID-19 vaccine access in New York City.](#)

[Physicians' attitudes and experiences with medical aid in dying in colorado: A "hidden population" survey.](#)

Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. *J Gen Intern Med.* 2022 Jan;11:1-8.

Debates arising in news and social media

[Public outrage over the unvaccinated is driving a crisis in bioethics](#)

Dyer E. *CBC news.* 22 janvier 2022

[Les responsables ont toujours tort](#)

Blanchette J. *Le Devoir.* 14 janvier 2022

[Predicting death could change the value of a life](#)

Schillace B. *Wired.* 28 décembre 2021

[How I became a sick person](#)

Douthat R. *The New York Times.* 23 octobre 2021

[Human genome editing requires difficult conversations between science and society](#)

University of Wisconsin-Madison. *Science Daily.* 26 avril 2021

[New report dissects ethics of emerging human brain cell models](#)

Heidt A. *The Scientist.* 12 avril 2021

User-oriented health ethics resources

[Health ethics and the Covid-19 pandemic: Recent and relevant literature](#)

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For more resources on pragmatic health ethics theory and practice, visit our website at [http://www.pragmatichealthethics.ca.](http://www.pragmatichealthethics.ca)



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