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

**Editorial team:**

Caroline Favron-Godbout Juliette Durocher  
Eric Racine, Ph.D.

[Pragmatic Health Ethics  
Research Unit,  
Institut de recherches  
cliniques de Montréal](#)

**PRAGMATIC  
HEALTH ETHICS  
RESEARCH UNIT**



**IRCM** Institut de recherches  
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**[Nouvelles de l'Unité de recherche en éthique pragmatique de la santé](#)**

### **Poste ouvert – Assistant.e de recherche technique (temps partiel)**

Nous sommes à la recherche d'un.e assistant.e de recherche technique souhaitant se joindre à l'Unité de recherche en éthique pragmatique de la santé à temps partiel. Les tâches incluent l'organisation de groupes de travail, la préparation de réunions de recherche, les dépôts au comité d'éthique de la recherche, le codage et l'analyse de données, la

révision d'articles, la réalisation de revues de littérature, ainsi que la préparation et le formatage de manuscrits. Poste d'une durée d'un an, avec possibilité de renouvellement pour une deuxième année. Le.a candidat.e aidera à établir des projets collaboratifs novateurs en éthique de la santé.

- Pour consulter l'offre d'emploi, [cliquez ici](#) .

### **Nouvelles publications:**

Quintal A, Carreau I, Grenier A, Hébert C, Yergeau C, Berthiaume Y, Racine E. An ethics action plan for rare disease care: participatory action research approach, J Particip Med. 2023;15:e46607 URL: <https://jopm.jmir.org/2023/1/e46607> DOI: 10.2196/46607

Cet article émerge d'un projet de recherche-action participative mené par Ariane Quintal, et présente un plan d'action pour améliorer les soins aux personnes vivant avec des maladies rares!

- Pour consulter l'article, [cliquez ici](#).

Padley N, Moubayed D, Lanteigne A, Ouimet F, Clermont MJ, Fournier A, Racine E. Transition from paediatric to adult health services: aspirations and practices of human flourishing, Int J Qual Stud Health Well-being. 2023;18(1), DOI: [10.1080/17482631.2023.2278904](https://doi.org/10.1080/17482631.2023.2278904)

Cet article émerge du [Projet Parachute](#) sur la transition des soins pédiatriques aux soins adultes.

Pour consulter l'article, [cliquez ici](#).

## Monthly profile

### **Victoria Seavilleklein, Ph.D.**

Victoria Seavilleklein is a clinical ethicist with Alberta Health Services. She has a Ph.D. in philosophy from Dalhousie University and several doctoral and post-doctoral fellowships in bioethics. Victoria leads ethics services for over 450,000 Albertans and 31 hospitals. Her role involves providing ethics consultation, education, policy review, and support for



organizational initiatives across all health care sectors, including acute care, continuing care and community care. She founded a province-wide education series that has run for 12 years and provided over 70 sessions on diverse topics. Victoria has contributed to the advancement of bioethics in Canada by organizing two national conferences and one national Forum, and serving 4 terms on the Board of the Canadian Bioethics Society- Société canadienne de bioéthique. Her interests include rural and community ethics, and social justice. She is currently engaged in moral distress work, with a particular interest in proactive approaches. Most recently, she co-led a national workshop exploring the nature of improvement of clinical ethicists, as part of a larger set of questions related to the professionalization of clinical ethics and the growth of the field.

### **Supporting sexual expression in continuing care facilities**

The COVID-19 pandemic forced us to confront the reality of our deep need for human connection and the detrimental effects of isolation. Without an equivalent global health justification, seniors in continuing care facilities have been isolated for decades when it comes to sexual expression. Societal stereotypes about sex and beauty being associated with youth, attitudes of staff and family members, and the lack of widespread policies or guidelines are some of the many barriers to the promotion of sexual expression in these settings.

Several ethical challenges require skillful navigation: changes in sexual preferences and behaviours in persons with dementia, residents with impaired cognition, partners with different levels of capacity, and providing private spaces, while also ensuring that residents are

protected from unwanted sexual attention and exploitation. Concern about possible risks of sexual expression – and particularly sexual activity – often eclipse consideration of the myriad known benefits to health, well-being and quality of life associated with wanted sexual activity, sexual expression, and intimacy. Preventing sexual behaviours against a resident's wishes can cause additional harms and distress.

Sexual desire continues across the lifespan and sexual rights of all persons are recognized by the World Health Organization. These needs should not be stifled due to living in a care facility. Successful strategies to support sexual expression include education for residents, staff, and family members, planning for resident sexual expression inclusive of diverse sexual orientations during intake and care planning, and the development of an environment that facilitates resident sexuality, including the creation both of opportunities for social interactions and for privacy. Guidelines can assist with navigating challenging scenarios in a way that enables care facilities to uphold their ethical obligations to all stakeholders while better supporting meaningful sexual expression for the adults under their care.

### **Selected publications:**

- Seavilleklein V, Flynn J, Frolic A, Wagner F, Lee-Ameduri. Do clinical ethicists improve with experience? And, if so, how would we know? *Can J Bioeth.* (forthcoming).
- Seavilleklein V. Challenging the rhetoric of choice in prenatal screening. *Bioethics.* 2009;23(1):68-77.
- Seavilleklein V & Sherwin S. The myth of the gendered chromosome: Sex selection and the social interest. *Camb Q Healthc Ethics.* 2007;16(1).

### **Professional Website:**

[John Dossetor Health Ethics Centre](#)

## 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.

### Special conference:

#### Tools for dialogue: a pragmatist approach to moral reasoning in health care and research

December 7, 2023 – 12PM to 1PM ET,  
Hybrid conference

Speaker: [Giulia Inguaggiato](#), PhD

To register in person, [click here](#).

To register online, [click here](#).

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Tools for dialogue: a  
pragmatist  
approach to moral  
reasoning in health  
care and research

**Giulia Inguaggiato, PhD**  
Department of Ethics, Law and  
Humanities, Amsterdam UMC

### [Call for proposals: 2024 CEREB-ACCER Conference “The future of research ethics: navigating the changing landscape”](#)

#### Canadian Association of Research Ethics Boards – Association canadienne des comités d'éthique de la recherche (CAREB-ACCER)

April 30, 2024 – May 2, 2024 (virtual event)

CAREB-ACCER is seeking speakers interested in sharing their expertise, knowledge, strategies, ideas and experiences with the Canadian research community for their 2024 virtual annual conference. The goal of the conference is to discuss, share learnings and equip attendees with knowledge, tools, capabilities and foundations in ethical considerations in the context of new and emerging topics of importance and relevance through. If you have any questions, comments, or concerns, please get in touch with the Conference Directors at [registration@careb-accer.org](mailto:registration@careb-accer.org).

To learn more, [click here](#).

To submit a proposal, [click here](#). Submission deadline:

December 22, 2023

**[Call for registration: Dossetor Health Ethics Seminar “The intelligent patients guide for cooperating with condescending physicians: a partnership rather than competition”](#)**

**John Dossetor Health Ethics Centre, University of Alberta**

December 14, 2023 – 2PM (ET)

Speaker: [Austin Mardon](#), PhD, CM, FRSC

The Health Ethics Seminars focus on emerging issues and themes in health ethics; equity, diversity and inclusion; and intersections of health ethics and health law. The speakers are usually affiliated with various healthcare disciplines, programs, and institutions, and have special expertise, practice and/or academic knowledge about specific ethical issues.

To register, [click here](#).

**[Call for application: Faculty Position, Bioethics – Full time](#) St. Jude Children's Research Hospital, Memphis, TN**

The growing St. Jude Section on Bioethics is recruiting a Faculty-level Bioethicist to support ongoing program development and serve as a consultative partner on bioethics issues to the St. Jude community. Under the supervision of the Section Director, the ethicist will collaborate with multidisciplinary teams in establishing the long term agenda for and developing resources related to the Section on Bioethics. Consultation responsibilities may include questions related to clinical care, research study design, international ethics, and other bioethics topics relevant to the St. Jude Mission. The ethicist will also contribute to the Section on Bioethics' program development and research agendas.

Internal Number: JR49878.

To learn more or to apply, [click here](#).

**[Call for registration: 2024 Healthcare Ethics Consortium \(HEC\) Annual Conference, “Limits, inclusion, and resilience: the ethics of caring”](#)**

**Healthcare Ethics Consortium (HEC)**

March 13, 2024 – March 14, 2024 (hybrid event)

The event will include 4 sessions: Session I – Ethical issues in caring for those with mental health concerns. Session II – Caring for those with critical illnesses and those near the end of life. Session III – Exploring the intersection of organizational and clinical ethics. Session IV – Promoting inclusion of and caring for those in marginalized communities. Onsite Location: Emory University Center for Ethics, 1531 Dickey Drive, Atlanta, GA 30322, 4047278307.

<https://ethics.emory.edu/>

To learn more, [click here](#). To register, [click here](#).

## Literature

### **Interdisciplinary foundations of health ethics**

#### [Towards a transactional medicine approach to combating global emerging pathogens: the case of COVID-19.](#)

Senghor A. S., Mbaye M. S., Diop R., Tosam M. J., Kabou P., Niang A., & Okoye G. *Glob Public Health*. 2023;18(1), 2272710. DOI: 10.1080/17441692.2023.2272710

#### [Objections to assisted dying within institutions: systemic solutions for rapprochement.](#)

Peisah C, Sheppard A, Leung KC. *BMC Med Ethics*. 2023;24(100). <https://doi.org/10.1186/s12910-023-00981-2>

#### [Bioethics issues of artificial placenta and artificial womb technology.](#)

Medori MC, Bonetti G, Donato K, Dhuli K, Henehan G, Brown R, Sieving P, Sykora P, Marks R, Falsini B, Capodicasa N, Miertus S, Lorusso L, Dondossola D, Tartaglia GM, Tartaglia GM, Ergoren MC, Dundar M, Michelini S, Malacarne D, Beccari T, Connelly ST, Martin D, Bacu A, Herbst KL, Kapustin M, Stuppia L, Lumer L, Farronato G, Bertelli M. *Clin Ter*. 2023 Nov-Dec;174(Suppl 2(6)):243-248. doi: 10.7417/CT.2023.2494.

#### [Disrespect in health care: an epistemic injustice.](#)

Beach MC. *J Health Serv Res Policy*. 2023 Nov 18:13558196231212851. doi: 10.1177/13558196231212851. Online ahead of print.

#### [Leaving no one behind: successful ageing at the intersection of ageism and ableism.](#)

Langmann E, Weßel M. *Philos Ethics Humanit Med*. 2023 Nov 24;18(1):22. doi: 10.1186/s13010-023-00150-8.

### **Methodologies and practices in health ethics**

#### [Experiences and preferences for learning about neonatal research: insights from parent interviews.](#)

Weiss EM, Porter KM, Oslin E, Puia-Dumitrescu M, Donohue PK, Merhar SL, Stephens E, Mercer A, Wilfond BS. *J Perinatol*. 2023 Nov 25. doi: 10.1038/s41372-023-01790-6. Online ahead of print.

**[Mapping MAiD discordance: a qualitative analysis of the factors complicating MAiD bereavement in Canada.](#)**

Serota K, Buchman DZ, Atkinson M. Qual Health Res. 2023 Nov 16:10497323231208540. doi: 10.1177/10497323231208540. Online ahead of print.

**[Exclusion of women from phase I trials: perspectives from investigators and research oversight officials.](#)**

Waltz M, Lyerly AD, Fisher JA. Ethics Hum Res. 2023 Nov-Dec;45(6):19-30. doi: 10.1002/eahr.500170.

**[Transition from paediatric to adult health services: aspirations and practices of human flourishing.](#)**

Padley N, Moubayed D, Lanteigne A, Ouimet F, Clermont MJ, Fournier A, Racine E. Intl J Qual Stud Health Well-being.2023;18(1). DOI: **[10.1080/17482631.2023.2278904](https://doi.org/10.1080/17482631.2023.2278904)**

**[Prioritization of research engaged with rare disease stakeholders: a systematic review and thematic analysis.](#)**

Yoon S, Lee M, Jung HI, Khan MM, Kim SY, Kim H, Wasti S. Orphanet J Rare Dis. 2023 Nov 23;18(1):363. doi: 10.1186/s13023-023-02892-2.

**Debates arising in news and social media**

**[La « sympathie » à l'égard des profs pèse dans la balance](#)**

Morasse M.-E. *La Presse*. 16 novembre 2023.

**[Aujourd'hui, on écrit l'histoire](#)**

Senneville C., Gingras É., Picard M., Comeau R., Bouchard J., Hubert M., & Bouvrette G. *Le Devoir*. 23 novembre 2023.

**[How new motherhood changed me as a doctor](#)**

Lamas D. J. *The New York Times*. November 26, 2023.

**[Et si Mike Ward avait raison ?](#)**

Collard N. *La Presse*. 23 novembre 2023.

For more resources on pragmatic health ethics theory and practice, visit our website at

**<http://www.pragmatichealthethics.ca>**