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# BRAINSTORM

**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  
CLINIQUES DE MONTRÉAL

## Profil du mois

### Marie-Pascale Pomey, M.D., Ph.D.

Marie-Pascale Pomey est médecin de santé publique, titulaire d'un Ph.D. en Santé publique de l'Université Paris V-Descartes et de l'Université de Montréal. Elle est professeure titulaire au Département de gestion, évaluation et politique de santé de l'École de santé publique de l'Université de Montréal où elle dirige l'option en gestion de la qualité et de la sécurité des soins (QUEOPSI) de la maîtrise en administration de la santé. Elle est titulaire de la [Chaire en évaluation des technologies et des modalités de pointe au Centre de recherche du Centre hospitalier de l'Université de Montréal](#) qui porte sur l'engagement des citoyens et des patients dans la transformation des organisations et du système de santé.



Son programme de recherche s'articule autour de trois axes : 1) le développement des meilleures méthodes d'engagement des patients aux différents niveaux de gouvernance du système de santé, 2) l'utilisation de la santé numérique pour favoriser le partenariat de soins au niveau clinique et 3) l'élaboration de stratégies de transferts de connaissance et d'outils de mesure du partenariat. Elle est aussi co-directrice du [Centre d'excellence sur le partenariat avec les patients et le public](#) (CEPPP) qui favorise la participation des patients et des citoyens dans les prises de décisions liées aux soins, ainsi que médecin conseil à l'[Institut national d'excellence en santé et en services sociaux](#) (INESSS). L'INESSS est une agence d'évaluation des technologies et des modes d'intervention en santé qui conseille le gouvernement et

recommande les meilleures pratiques pour le système de santé.

## **Une réflexion éthique sur les patients accompagnateurs**

Depuis plusieurs années, je m'intéresse à l'introduction de patients dits accompagnateurs dans les équipes cliniques. Les patients accompagnateurs sont des personnes ayant vécu des soins de santé et qui mettent à profit leur savoirs expérientiels avec la maladie, les traitements et l'utilisation du système de santé pour d'autres personnes aux prises avec les mêmes problématiques. Jusqu'à présent, l'introduction de patients accompagnateurs s'est effectuée lors de la transition entre la médecine pédiatrique et adulte, l'insuffisance rénale, les grands-brûlés, la réadaptation suite à une chirurgie d'urgence de la main et la cancérologie. L'arrivée de ces nouveaux acteurs dans le système de santé pose de nombreux enjeux éthiques et juridiques qu'il est important de prendre en considération pour optimiser cette intégration.

J'ai donc travaillé avec Catherine Régis (Faculté de droit, Université de Montréal) et Isabelle Ganache (INESSS) pour identifier 8 enjeux :

1. Protéger les acteurs impliqués dans un programme faisant appel à des patients accompagnateurs ;
2. Assurer le caractère éclairé, libre et continu des consentements dans la relation entre le patient accompagnateur et le patient accompagné ;
3. Protéger la vie privée et la confidentialité des patients ;
4. Assurer la confiance dans les programmes faisant appel à des patients accompagnateurs ;
5. Recruter adéquatement les patients accompagnateurs ;
6. Former les patients accompagnateurs pour assurer la qualité de l'accompagnement ;
7. Reconnaître la contribution des patients accompagnateurs;
8. Affirmer les fondements éthiques du programme de patients accompagnateurs.

Cette innovation, en prenant en considération ses enjeux éthiques, permet aux patients accompagnateurs : 1) de questionner les modalités d'organisation des soins et des services et amener des pistes de solutions pour les améliorer, 2) de sensibiliser les professionnels aux questionnements et aux vécus des patients afin de les aider à encore mieux y répondre et 3) d'aider les patients à être moins anxieux par rapport à leur maladie et leur traitement pour ainsi à être plus disposés à rentrer en partenariat avec leur professionnels de santé. Les patients accompagnateurs comme membres à part entière de l'équipe humanise les soins.

## **Publications sélectionnées**

**Pomey MP**, Brouillard P\*, Ganache I, Lambert L, Boothroyd L, Collette C, Bédard S, Grégoire A, Pelaez S, Demers-Payette O, Goetghebeur M, de Guise M, Roy D. (2019). [Co-construction of health technology assessment recommendations with patients: An example with cardiac defibrillator replacement](#). Health Expectations.

**Pomey MP**, Flora L, Karazivan P., Dumez V, Lebel P, Vanier M-C, Jouet E. (2015). [Le « Montreal model » : enjeux du partenariat relationnel entre patients et professionnels de la santé](#). Santé Publique, 2015/HS S1, p. 41-50.

Pomey MP, Dumez V et Denis JL. (2019). [Patient engagement: How patient-provider partnerships transform healthcare organizations](#). New SHOC Monograph Series: Organisational Behaviour in Healthcare.

## Pour plus d'information

Site Web : <https://chaireengagementpatient.openum.ca>

Facebook : <https://www.facebook.com/chaireengagementpatient/>

Twitter : [@ParolePatient](#) et [@MP2\\_](#)

## Events and Announcements

### [The Montreal Health Ethics Conference Series](#)

This bilingual monthly conference/webinar series aims to bring people together to think about and discuss issues in health ethics. Our aim is to promote health ethics through conferences that foster dialogue between groups of participants with different perspectives (e.g., academics, clinicians, patients, community members). These seminars appeal to audiences both within and outside of academia and healthcare settings with the goal of increasing mutual awareness about health ethics and promote interdisciplinary and community reflections on various cross-cutting health ethics topics.

The theme of our series for the year 2019-2020 is: ***The role of dialogue in care and in the healthcare system***. How can our health system and health professionals be more attentive to patients? Should they be and why? Which changes are needed in healthcare and in the health system? What are the challenges of dialogue and deliberation for patients or between team members, or even within a single institution or network of care? Our guests will address these questions (amongst others) while sharing their vision regarding the issues surrounding ethical deliberation in health and taking particular interest in decision-making processes, relationships between patients and health professionals, caring for marginalized populations, and more.

**Notre prochaine conférence (qui sera diffusée en direct sur notre [chaîne YouTube](#)):**

**26  
MARS**

**12<sup>H</sup>  
P.M.**

Auditorium Jacques-Genest  
Institut de recherches cliniques de Montréal  
110, avenue des Pins Ouest

SÉRIE DE CONFÉRENCES DE MONTRÉAL  
EN ÉTHIQUE DE LA SANTÉ

**2019-2020**

MONTREAL HEALTH ETHICS  
CONFERENCE SERIES

**Quelle place pour le dialogue dans les soins  
et le système de santé ?**

Is there a place for dialogue in healthcare and health  
systems?



## Le dialogue, l'advocacy et la détresse morale des soignants

### Une conférence de Jocelyne Saint-Arnaud

Professeure associée à la Faculté des sciences  
infirmières de l'Université de Montréal et chercheure  
associée au Centre de recherche en éthique et  
à l'Institut de recherche en santé publique de  
l'Université de Montréal.

*A lecture by Jocelyne Saint-Arnaud, associate professor of the  
nursing faculty of Université de Montréal and associate researcher  
at Centre de recherche en éthique and at Institut de recherche en  
santé publique of Université de Montréal.*

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Here is the schedule of all our upcoming conferences in 2020:

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26 MARS 2020 – MARCH 26, 2020

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**JOCELYNE SAINT-ARNAUD**

Le dialogue, l'advocacy et la détresse morale des soignants

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9 AVRIL 2020 – APRIL 9, 2020

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**JEAN ROCHON**

**MICHEL CLAIR**

Panel de discussion où deux anciens ministres québécois s'entreprendront sur les valeurs au cœur de notre système de santé et sur l'importance du dialogue public pour l'avenir de notre système de santé au Québec.

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1ER JUIN 2020 – JUNE 1ST, 2020\*

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**ALBERT CHRISTIAAN MOLEWIJK**

Reflections on ethical deliberation and the dialogical approach at the heart of healthcare.

\*Exceptionnellement à 11 h 30 / Exceptionally at 11:30 A.M.

All conferences will be livestreamed on our [YouTube Page: Pragmatic Health Ethics](#).

**[Hacking the Mind: How Technology Is Changing The Way We View Our Brain and Ourselves](#)**

**2020 Dana Foundation Brain Awareness Week Distinguished Neuroethics Lecture**

**Date:** March 16, 2020, 5:30 PM – 6:00 PM

**Location:** C300 Theatre, UBC Robson Square, 800 Robson Street, Vancouver, BC, V6Z 3B7

As it advances, our relationship with brain technology will change. In this lecture, Dr. Nir Lipsman will discuss how our knowledge of brain circuitry, and how it can go wrong, has informed our understanding of human behaviour. We will then discuss the implications of more sophisticated, precise and less intrusive brain technology, on that relationship, and what it could all mean for the next generation of brain therapy and beyond.

Nir Lipsman, MD, PhD, FRCSC is a neurosurgeon and scientist at Sunnybrook Health Sciences Centre and an Assistant Professor of Surgery at the University of Toronto. He completed his undergraduate degree at the University of Toronto followed by a medical degree at Queen's University, and a neurosurgical residency at the University of Toronto. During his residency, Dr. Lipsman completed his PhD investigating novel neuromodulation strategies in patients with treatment-resistant psychiatric and neurologic conditions. He is currently the Director of Sunnybrook's Harquail Center for Neuromodulation, and the Clinical Director of Sunnybrook's Focused Ultrasound Centre of Excellence.

This public event is FREE, but tickets are required and [available here](#).

**[Call for Applications: Director of Ethics Center / Program](#)**  
**Medical University of South Carolina**

## **Charleston, South Carolina, United States**

Job summary and purpose: The Director of Ethics Center/Program reports to the Chief Quality Officer. Under indirect supervision, the Director of Ethics Center/Program demonstrates a commitment to improving health care quality by facilitating the resolution of ethical concerns. This role is responsible for the planning, operation and evaluation of ethics education, consultation and integration throughout the enterprise, scope of practice includes providing individual ethics consults, serving on the ethics committee and consultation teams and working closely with existing programs where ethical issues arise.

Minimum training and education: MD, PhD, or Master's degree in philosophical ethics, ethics/bioethics; or equivalent in an area of study related to bioethics (such as medicine, philosophy, law, sociology, medical anthropology). A minimum of one year of advanced experience with ethics committees (e.g. as chair or co-chair), including performance of ethics consultations required. Demonstrated leadership experience in a university-level ethics program preferred. Candidate should be an established scholar with publications and presentations in the field of bioethics.

**Deadline:** March 31, 2020

### **[Call for Applications: Research Faculty](#)**

**Center for Bioethics, Harvard Medical School**

**Boston, Massachusetts, United States**

The Center for Bioethics at Harvard Medical School is recruiting faculty to expand our research portfolio in bioethics. Appointment as an Instructor, Assistant or Associate Professor at Harvard Medical School, commensurate with training, experience, and achievements. Candidates must have a terminal degree in an academic discipline related to bioethics, such as medicine, health policy, sociology, anthropology, economics, philosophy, history, or law, among others. The successful candidate will have demonstrated success at obtaining and completing funded research, with mentorship of junior faculty and students. The position will include an attractive start-up package that will support the candidate in initiating a program of research, with future support relying upon a combination of grant funding and institutional support. While the primary focus of the position is to develop and grow a funded research portfolio in bioethics, the successful candidate will also engage in opportunities to teach and mentor within the Center's broad range of activities, as described on the Center for Bioethics' website (<https://bioethics.hms.harvard.edu/>).

The position will be based in both the Center for Bioethics at Harvard Medical School and at the Mongan Institute ([www.MonganInstitute.org](http://www.MonganInstitute.org)) in the Department of Medicine at Massachusetts General Hospital offering an extraordinary academic, applied research, and clinical environment for collaboration and scholarship. Interested individuals should submit a letter of interest and their Curriculum Vitae to: Robert Truog, Director, Center for Bioethics, Harvard Medical School, [bioethicssearch@hms.harvard.edu](mailto:bioethicssearch@hms.harvard.edu). The search will remain open until a successful candidate is found.

## **[Call for Applications: PhD Scholarship in Neuroethics or Bioethics](#)**

**University of Tasmania**

**Hobart, Tasmania, Australia**

Merging human beings with machines via artificially intelligent brain-computer interfaces is a major scientific achievement of the current decade. It holds the key to countless new therapeutic applications from using thoughts to manoeuvre robotic limbs to controlling psychiatric symptoms. This project aims at exploring, identifying and translating a range of potential postoperative-related vulnerabilities introduced by AI brain-computer interfaces, especially those related to the notion of agency, autonomy, responsibility, estrangement, identity, privacy, and ownership. This project will develop new knowledge around understanding the phenomenology of brain-computer interfaces, but as well harm prevention in the future use of AI applications in medicine, cognitive science and neurology.

**Deadline:** March 31, 2020

## **[Call for Applications: Postdoctoral Fellow in Biomedical Ethics / Clinical Trials](#)**

**Biomedical Ethics Unit / Social Studies of Medicine, McGill University**

**Montreal, Quebec, Canada**

**[McGill Biomedical Ethics Unit / Studies of Translation, Ethics, and Medicine](#)** (STREAM) is inviting applications for two postdoctoral research fellows (PDFs) with a background in research ethics, epidemiology, biostatistics, or meta-research.\* Priority will be given to candidates with demonstrate knowledge of clinical trials and drug regulation, and a penchant for interdisciplinary work. One project will examine inefficiencies in drug development, ethical oversight, and drug approval. The other project will explore methods of improving decision-making in the design and review of cancer drug trials. Both projects involve a mix of empirical and conceptual methods. The PDFs will work under the supervision of Jonathan Kimmelman, alongside co-investigators with expertise in Philosophy, Epidemiology/Biostatistics, and Cancer. Applications should include a cover letter describing research interests, a CV, a writing sample, and the contact information for 3 references. Applicants who do not have a completed Ph.D. at the time of application must include a letter from their Department Chair specifying the date of their dissertation defense. Applications should be sent electronically to Jonathan Kimmelman, PhD at [jonathan.kimmelman@mcgill.ca](mailto:jonathan.kimmelman@mcgill.ca).

**Deadline:** Review of applications will proceed on a rolling basis and will continue until the positions are filled.

## **[Call for Abstracts: 21st International Nursing Ethics Conference and 6th International Care Ethics Conference](#)**

**June 6 and 7, 2020**

**Toronto, Ontario, Canada**

This year's conference theme examines the place of conscientious commitment and resistance in building and sustaining moral agency within current healthcare systems. These practices require that nurses and other healthcare practitioners provide needed care in the face of the



perception of unjust laws and policies, social disapproval, and/or a lack of organizational support. How can these practices be fostered? What are their limits? How are they related to professional identity? Issues related to the conference theme will be addressed by international experts and scholars in the field of ethics and nursing. Ample opportunity will be afforded for interactive dialogue and discussion with keynote speakers and panelists. Practitioners, researchers, educators, managers and students in the field of health and social care from around the world are invited to attend and participate in this conference to engage in ongoing discussions about these questions in relation to how ethical care can best be sustained in the context of issues related to conscientious commitment and resistance. To submit a proposal for an oral presentation, [click here](#).

**Deadline:** March 9, 2020

## Literature

### Interdisciplinary foundations of health ethics

#### [The legacy of language: Disfigurement bias in the NICU.](#)

Kett JC, Cunningham ML, Wightman A. *Acta Paediatr.* 2020 Feb 19. [Epub ahead of print]

#### [Covert administration of medication in food: a worthwhile moral gamble?](#)

Guidry-Grimes L, Dean M, Victor EK. *J Med Ethics.* 2020 Feb 14. [Epub ahead of print]

#### [Equitable access to ectogenesis for sexual and gender minorities.](#)

Kimberly LL, Sutter ME, Quinn GP. *Bioethics.* 2020 Feb 12. doi: 10.1111/bioe.12723. [Epub ahead of print]

#### [Defining life from death: Problems with the somatic integration definition of life.](#)

Blackshaw BP, Rodger D. *Bioethics.* 2020 Feb 3. [Epub ahead of print]

#### [Shaping the CRISPR gene-editing debate: Questions about enhancement and germline modification.](#)

Johnston J. *Perspect Biol Med.* 2020;63(1):141-154.

### Methodologies and practices in health ethics

#### [Early experience with medical assistance in dying in Ontario, Canada: a cohort study.](#)

Downar J, Fowler RA, Halko R, Davenport Huyer L, Hill AD, Gibson JL. *CMAJ.* 2020 Feb 11. [Epub ahead of print]

#### [Transparent defaults and consent for participation in a learning health care system: An empirical study.](#)

Dranseika V, Piasecki J. *J Empir Res Hum Res Ethics.* 2020 Feb 11. [Epub ahead of print]

#### [The concept of vulnerability in mental health research: A mixed methods study on researcher perspectives.](#)



Lajoie C, Poleksic J, Bracken-Roche D, MacDonald ME, Racine E. *J Empir Res Hum Res Ethics*. 2020 Feb 10. [Epub ahead of print]

**[A novel peer-directed curriculum to enhance medical ethics training for medical students: A single-institution experience.](#)**

Sullivan BT, DeFoor MT, Hwang B, Flowers WJ, Strong W. *J Med Educ Curric Dev*. 2020 Jan 22;7:2382120519899148. eCollection 2020 Jan-Dec.

**[A matter of time: grappling with everyday ethical tensions at the confluence between policy and practice in a psychiatric unit.](#)**

Motta-Ochoa R, Lencucha R, Xu J, Park M. *J Med Ethics*. Published Online First: 2019 Dec 12. [Epub ahead of print]

## News and social media

**[Ottawa veut élargir l'aide médicale à mourir.](#)**

Buzzetti H. *Le Devoir*. February 25, 2020.

**[She didn't want a pelvic exam. She received one anyway.](#)**

Goldberg E. *The New York Times*. February 17, 2020.

**[The coronavirus outbreak exposes the U.S.'s pharma supply chain vulnerability.](#)**

Blackburn M. *STAT News*. February 14, 2020.

**[Avortements tardifs au Québec: Mieux encadrer l'exception](#)**

Perreault LJ. *La Presse*. February 9, 2020.

**[Is medically assisted dying a choice if persons with disabilities aren't given the necessary supports to live?](#)**

Severino SM. *The Star*. January 28, 2020.

## Other resources

For more resources on pragmatic health ethics theory and practice, visit our website at <http://www.pragmatichealthethics.ca>.

