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## Brainstorm Newsletter

An Interdisciplinary Newsletter about Advances in Health Ethics Theory and Practice -

December 2018

Volume: 11, Issue: 12

Please note that this issue of Brainstorm is the last of 2018. **Brainstorm will not publish a January 1st edition**, but will be back on **February 1st, 2018**.

Happy Holidays!

Veillez prendre note que ce numéro de Brainstorm représente le dernier numéro avant le Nouvel An. **Nous ne publierons pas une édition du premier janvier**. La prochaine édition de Brainstorm sera expédiée le **1er février 2018**.

Joyeuses fêtes!

## Editorial Team

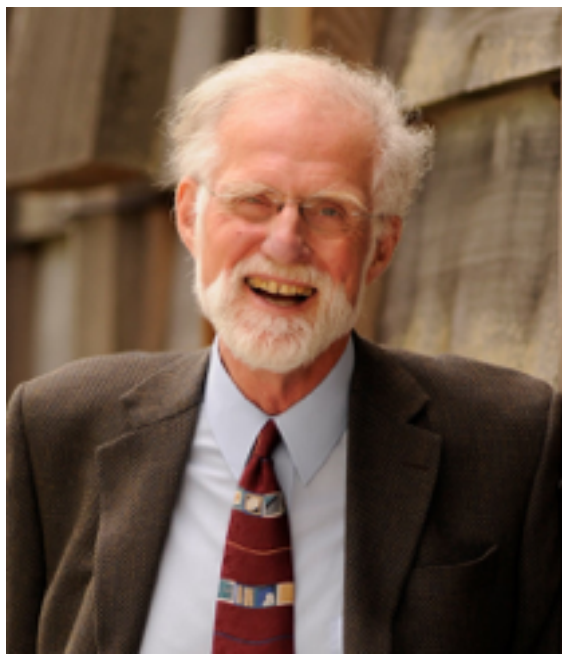
- Claudia Barned
- John Aspler
- Matthew Sample
- Corinne Lajoie
- Eric Racine (editor-in-chief)

**PRAGMATIC  
HEALTH ETHICS  
RESEARCH UNIT**



## Profile of the Month

Michael McDonald, PhD



When I started my academic career in 1969, I focussed on ethical theory as viewed through a philosophical lens. Little did I realize that years later I would be part of the collective effort that created a strong Canadian presence in interdisciplinary bioethics research and practice. My contribution to that effort took a number of forms: writing the report that led to a SSHRC funding program for applied ethics, establishing the UBC Centre for Applied Ethics, helping draft the first version of the TCPS Guidelines on human research protection, working in CIHR and other bodies to support ethical research and practice, and the creation of a large body of

collaborative work in bioethics, especially in research ethics. Looking back now, I am deeply grateful for the opportunity to have worked with and learned so much from bioethics colleagues and students across Canada.

**Short Statement:** Since my involvement with the creation of the TCPS research ethics guidelines in the mid-1990's, I have been concerned with how such policy structures are put into practice and achieve their stated ends. In a series of publications starting with the report to the then Law Commission of Canada on *The Governance of Health Research Involving Human Subjects* (2000), I reached a number of conclusions.

First, the focus on participant protection has been on rule compliance. Actual outcomes for participants are not tracked. Instead potential outcomes are guesstimated by REBs.

Second, the means for participant protection – the Research Ethics Board – has come to be confused with the end – actual effective protection. Researchers commonly talk about “getting through ethics” as a matter of securing REB approval and collecting signed consent forms. Research sponsors, regulators and institutions treat REB review as the sum and substance of research ethics. The absence of visible complaints has been taken as evidence of success.

Third, there are significant gaps between what participants actually experience in research and what researchers and REBs think they experience.

What is needed is an effective evidence-based approach to research participant protection centred on impacts on participants. Here is where I think that bioethics researchers can make a major contribution by gathering evidence about the experiences and values of participants across the broad range of health research and seeing how well they fit with what researchers, REB members, and regulators think they experience and value.

#### **Publications:**

1. Cox, S. M., & McDonald, M., Ethics is for human subjects too: Participant perspectives

on responsibility in health research, *Social Science & Medicine* (2013),

<http://dx.doi.org/10.1016/j.socscimed.2013.09.015>

2. McDonald, M., Townsend, A., Cox, S. M., Patterson N. D., & Lafrenière, D. "Trust in Health Research Relations: Accounts of Human Subjects," *Journal of Empirical Research on Human Research Ethics* (2008), 3, 4 pp. 35–47.
3. McDonald, M. "Canadian Governance of Health Research Involving Human Subjects: Is Anybody Minding the Store?" *Health Law Journal*, Vol.9, 2001, pp. 1-21.

## Events and Announcements

### [Montreal Health Ethics Seminar Series](#)

The Montreal Health Ethics Seminar Series featured its second seminar on November 29th, 2019 with an engaging presentation by Dr. Annie Janvier from CHU St. Justine. The seminar series is a bilingual monthly seminar/webinar series aimed at bringing people together to think about and discuss issues in health ethics. Our aim is to promote health ethics through seminars that foster dialogue between groups of participants with different perspectives (e.g., academics, clinicians, patients, community members). These seminars will 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.

Join us for our next seminar/webinar in January:

**When:** January 31st, 2019, 12-1PM

**Where:** Institut de recherches cliniques de Montréal (110 avenue des Pins Ouest, Auditorium Jacques Genest) OR livestreamed through our [YouTube page: Pragmatic Health Ethics](#)

**What:** Dr. Annie Pullen- Sansfaçon "What is our responsibility with regard to the care of transgender youth?"

All conferences are free and require no registration!

Visit our website or email us for more information about where seminars will be archived for future viewing or educational use (e.g., journal clubs, classroom, continued education):

<http://www.pragmatichealthethics.ca/outreach/montreal-health-ethics-seminar-series/>

### [Neurotechnology Meets Artificial Intelligence - Call for Papers](#)

The conference brings together a wide range of scholars with various disciplinary backgrounds (philosophy, law, social science, cognitive sciences, medicine) to discuss the multi-dimensional implications of Neurotechnology and AI. The event will take place from May 8-10, 2019 in Munich, Germany. It is organized by the INTERFACES projects at the Institute for Ethics, History and Medicine at the Ludwig-Maximilians Universität (LMU)

Munich.

Neurotechnologies such as brain-computer interfaces (BCIs) are no longer a futuristic dream, or depending on the viewpoint, a nightmare. They are subject of many research projects and their usability improves rapidly. Today, BCIs represent an important tool for a wide range of medical applications. For instance, they enable otherwise disabled patients to communicate by using a computer via brain activity.

**Submission deadline: January 15th, 2019.**

### **[Critical Issues in Science and Technology Studies - Call for Papers](#)**

The 18th Annual STS Conference Graz 2019 invites interested researchers in the areas of Science, Technology and Society Studies (STS) and Sustainability Studies to give presentations. The conference provides a forum to discuss on a broad variety of topics in these fields - especially abstracts are encouraged which include some aspects of the above mentioned conference themes or special sessions.

The STS Conference Graz 2019 is the joint Annual Conference of the Science Technology and Society Unit of the Institute of Interactive Systems and Data Science of the Technical University of Graz, the Inter-University Research Centre for Technology, Work and Culture (IFZ) and the Institute for Advanced Studies of Science, Technology and Society (IAS-STS).

**Submission deadline: January 21, 2019.**

### **[Postdoctoral Fellow - The Pragmatic Health Ethics Research Unit - Call for Applications](#)**

The Pragmatic Health Ethics Research Unit is seeking TWO (2) postdoctoral fellows or graduate students to work on two main projects. The first project examines the ethical and social implications of health care transitions for youth with chronic conditions, including rare diseases. The second project examines the ethics of registry-based type-1 diabetes research.

**Applications will be reviewed on an ongoing basis until the position is filled.**

### **[Postdoctoral Fellow - Neuroethics Canada - Call for Applications](#)**

A postdoctoral fellow position is available immediately for a highly motivated PhD graduate to join a dynamic research team devoted to issues related to brain health, technology and patient experience. The position is based out of BC Children's and Women's Hospital in Vancouver, BC. The successful individual will work closely with the PI, the Alzheimer's Society of BC, and other members of the project team to explore the strengths and areas for improvement of a provincial dementia support program.

Applications will be reviewed on an ongoing basis until the position is filled.

### [Tenure Track Assistant Professor Position - UNC Chapel Hill - Call for Applications](#)

UNC Chapel Hill invites applications for the position of Assistant Professor in Technology Studies beginning July 1, 2019. Responsibilities include teaching undergraduate and graduate courses in media and technology studies, conducting research, supervising dissertations, performing departmental, university and public service. Salary is competitive.

Submission deadline: December 20th, 2018.

### [Tenure Track Assistant/Associate Professor Position - University of Washington - Call for Applications](#)

The University of Washington is recruiting for a full-time (100% FTE, 12-month service period), tenure-track faculty position in the School of Medicine of the Department of Bioethics & Humanities at Assistant or Associate Professor level, commensurate with experience and qualifications.

Anticipated start date is summer/early fall 2019.

Submission deadline: January 14th, 2019.

### [Tenure Track Assistant Professor Position - Xavier University of Louisiana - Call for Applications](#)

The College of Arts and Science at Xavier University of Louisiana (XULA) invites applications for a full-time tenure-track entry-level Assistant Professor position in the area of Medical Humanities beginning Fall 2019. The successful candidate is expected to teach effectively, advise students and conduct and publish independent and collaborative research.

Review of applications will begin on January 7th, 2019.

## Literature

### Interdisciplinary Foundations of Health Ethics

#### [Creating the Safety and Respect Necessary for "Shared" Decision-making.](#)

Halpern J. Pediatrics. 2018 Nov; 142(Suppl 3): S163-9.

#### [A Philosophical Approach to Addressing Uncertainty in Medical Education.](#)

Tonelli MR, Upshur REG. Acad Med. 2018 Oct 30. [Epub ahead of print].

[Embedded Journalists or Empirical Critics? The Nature of The "Gaze" in Bioethics.](#)

Ashby MA, Morrell B. J Bioeth Inq. 2018 Sep; 15(3): 305-7.

[When I say... moral distress as a teaching point.](#)

Waldman RA, Waldman SD, Carter BS. Med Educ. 2018 Nov 14. [Epub ahead of print].

[Legal capacity, mental capacity and supported decision-making: Report from a panel event.](#)

Craigie J, Bach M, Gurbai S, Kanter A, Kim SYH, Lewis O, Morgan G. Int J Law Psychiatry. 2018 Oct 31. [Epub ahead of print].

## **Methodologies and Practices in Health Ethics**

[Standardizing return of participant results.](#)

Botkin JR, Appelbaum PS, Bakken S, Brown C, Burke W, Fabsitz R, Gamble VN, Gonsalves G, Kost R, Leonard DGB, McGuire A, Nichols JH, Patrick-Lake B, Wilkins CH, Zikmund-Fisher BJ. Science. 2018 Nov 16; 362(6416): 759-60.

[Metrics and Evaluation Tools for Patient Engagement in Healthcare Organization- and System-Level Decision-Making: A Systematic Review.](#)

Dukhanin V, Topazian R, DeCamp M. Int J Health Policy Manag. 2018 May 16; 7(10): 889-903.

[Conflicts of interest and the \(in\)dependence of experts advising government on immunization policies.](#)

Bélisle-Pipon JC, Ringuette L, Cloutier AI, Doudenkova V, Williams-Jones B. Vaccine. 2018 Nov 26; 36(49): 7439-44. Epub 2018 Oct 22.

[Addressing Medical Students' Negative Bias Toward Patients With Obesity Through Ethics Education.](#)

Geller G, Watkins PA. AMA J Ethics. 2018 Oct 1;20(10):E948-959.

[Patient Perspectives on the Value of Patient Preference Information in Regulatory Decision Making: A Qualitative Study in Swedish Patients with Rheumatoid Arthritis.](#)

Bywall KS, Veldwijk J, Hansson MG, Kihlbom U. Patient. 2018 Nov 15. [Epub ahead of print]

## **News and Social Media**

[Medical Ethics: "When a Dying Patient Confesses to Murder"](#)

Neuroskeptic. Discover Magazine. November 18, 2018.

[Trans Communities In Canada Need More Than Just Legislative Rights](#)

Johnstone F. Huffington Post Canada. November 16, 2018.

[Why bigotry is a public health problem](#)

Pies RW. The Conversation. November 21, 2018.

[Meet Zora, the robot caregiver](#)

Satariano A, Peltier E, Kstyukov D. The Toronto Star. November 27, 2018.

[How Justin Clark's fight for independence transformed disability rights in Canada](#)

Gutnick D. CBC Radio. November 25, 2018.

[Chinese Scientists Are Outraged by Reports of Gene-Edited Babies](#)

Zhang S. The Atlantic: Science. November 27, 2018.

[Chinese Scientist Who Says He Edited Babies' Genes Defends His Work](#)

Belluck P. The New York Times. November 28, 2018.



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