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Brainstorm Newsletter

An Interdisciplinary and Bilingual Newsletter about Advances in Health Ethics Theory and Practice - February 2020

Volume: 13, Issue: 1

Editorial Team

- Ariane Quintal
- Eric Racine

**PRAGMATIC
HEALTH ETHICS
RESEARCH UNIT**



Profile of the Month

M. Ariel Cascio, Ph.D.

Interdisciplinary work like that featured in Brainstorm is central to my work. I am currently Assistant Professor in the Art of Medicine at Central Michigan University College of Medicine, where I teach ethics, social sciences, and research methods to first and second year medical students. Prior to starting this position, I was a postdoctoral fellow at the Pragmatic Health Ethics Research Unit, and from 2018-2019 an SSHRC Banting Postdoctoral Fellow. My postdoctoral research focused on ethical issues around autism, including collaborative moral deliberation on research ethics issues and a multi-method survey of service preferences of autistic adults and parents of people with autism. This research followed up on and complemented my doctoral research in anthropology, on the experiences of adolescents and youth accessing autism services in Italy. More recently, I have co-edited the book below with Eric Racine, which was published in November 2019.



Q&A: Research Involving Participants with Cognitive Disability and

Differences

1. What is your new book about?

This edited volume brings together conceptual and empirical work around the theme of ethics in research involving participants with cognitive disability or difference, focusing especially on participants with intellectual and developmental disability, neurodegenerative conditions, and psychiatric diagnoses. The book opens with a series of conceptual chapters on topics including legal options for research decision-making for people with impaired consent capacity (Wright) and “errors in consent” experienced by typically developed persons that calls into question to notion of a ideal consentor (Barnbaum). Several chapters then describes challenges researchers have faced in conducting research involving people – participants or researchers – with cognitive disability and difference, as well as successes. The book concludes with commentaries by the authors of these other chapters as well as prominent scholars in neuroethics, law, and more.



2. What do you hope to accomplish with this new volume?

We hope this book will be of interest to researchers as well as potential research participants or gatekeepers who want to understand the inner workings of research studies. We knew there were a lot of researchers doing innovative work, and we are happy so many of them have agreed to contribute to this volume.

3. What are new topics to address to foster inclusion and participation in research?

Although some of the chapters address this (e.g., Kohler and Majewski), I would like to see even more work available on the experiences of researchers with cognitive disability and difference. I would also like more research on the perspectives of research participants – or those who are asked but decline to participate in research. This research doesn't need to be about how to convince non-participants to participate – although it can help in identifying barriers to participation that should be removed. It can also inform the creation of inclusive consent processes that truly empower potential participants to say yes or no.

Selected publications

Cascio, M.A. and E. Racine. 2018. Person-Oriented Research Ethics: Integrating Relational and Everyday Ethics in Research. *Accountability in Research* 25(3):170-197.

Cascio, M.A., B. Costa Andrada, B. Bezerra Jr. 2018. “Psychiatric Reform and Autism Services in Italy and Brazil.” In *Autism in Translation: An Intercultural Conversation on Autism Spectrum Conditions*, edited by E. Fein and C. Rios, 53-87. Cham, Switzerland: Palgrave MacMillan.

Cascio, M.A. 2015. Rigid Therapies, Rigid Minds: Italian Professionals' Perspectives on Autism Interventions. *Culture, Medicine and Psychiatry* 39(2):235-253.

Websites

[Wordpress Website](#)

[Autism Research Ethics](#)

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.

Our next conference (also livestreamed on our [YouTube channel](#)):

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?

**13
FÉV.**

**12^H
P.M.**

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

Micro-reconciliation as a Pathway for Transformative Change

A lecture by Caroline Tait, member of the Métis Nation of Saskatchewan and professor in the Department of Psychiatry, University of Saskatchewan.

Une conférence de Caroline Tait, membre de la Nation Métis de Saskatchewan et professeure au département de psychiatrie de l'Université de Saskatchewan.

This lecture focuses on the micro-reconciliatory refashioning of interpersonal interactions between First Nations, Inuit and Métis peoples with Canada's settler population. It examines micro-reconciliation as a form of change needed to enhance and advance cultural safety work and humility across the human service sector, as well as challenge and diminish manifest racism, inequality and inequity experienced by Indigenous peoples. The talk focuses on the intersections between entrenched structural racism and the psychological and emotional roots of discrimination existent in services provided to Indigenous peoples, and how this calls for a need for broader structural reform.



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

13 FÉVRIER 2020 – FEBRUARY 13, 2020

CAROLINE TAIT

Ethical considerations of inadequate access to health services for Canadian Indigenous populations. How can dialogue play a determining role?

26 MARS 2020 – MARCH 26, 2020

JOCELYNE SAINT-ARNAUD

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

9 AVRIL 2020 – APRIL 9, 2020

**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.

1ER JUIN 2020 – JUNE 1ST, 2020*

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](#).

[Call for Proposals: The Pragmatic Health Ethics Research Unit's Brainstorm Magazine](#)



This year, the Pragmatic Health Ethics Research Unit is launching the second issue of [Brainstorm Magazine](#), a bilingual online open-access publication on health ethics in Canada and abroad. The theme of Issue 2 is dialogue; it is intended to bring together diverse perspectives (academic, journalistic, personal, and beyond) on the role of dialogue and collective deliberation in the healthcare system and/or in the patient-clinician relationship. Click [here](#) for more details. Given that the Brainstorm Magazine targets a broad audience, we will be

encouraging all contributors to write in an accessible way, without jargon. Our editorial team will be available to help with this via one or two round(s) of edits. If you are interested in submitting a contribution, please send a short contribution proposal (200 words) and a brief biography to pragmatic.health.ethics@ircm.qc.ca. Those whose contributions will be accepted will receive a modest compensation.

Deadline for submitting a short contribution proposal and a brief biography: February 20, 2020.

[Call for Abstracts: Bridging Science, Health, and the Environment: Problems of Knowledge or Politics? - STS Workshop](#)

April 29-30, 2020

Institut de recherches cliniques de Montréal, Montreal, Quebec, Canada

Are science and technology effective means of solving society's most pressing problems? Can they live up to the common promise of protecting health and the environment? If not, what is missing and how might we reframe a productive relationship between science and society, between knowledge-creation and political processes? Supported by SSHRC, the Institut de recherches cliniques de Montréal and the Institute for Science, Society and Policy (University of Ottawa), the [Canadian Network for Science and Democracy](#) is pleased to announce its second workshop (April 29-30). With the aim of developing the capacity of science and technology studies (STS) to understand and respond to societal challenges, we welcome talk proposals from both established researchers and graduate students. Submissions can employ any (inter)disciplinary perspective, empirical or theoretical, so long as they critically address one of the workshop themes: technoscience, societal challenges, and solutions; (dis)entanglements of knowledge practices and politics; ethics and shared values in science; evidence-informed policy; techno-solutionism; and related topics.

Workshop discussions will be anchored in a keynote presentation from Dr. Stephen Hilgartner (Department of STS, Cornell University) and a bilingual café scientifique event. Several travel bursaries will be available, with some reserved for students or early career researchers. The workshop will include approximately 10 papers and a roundtable dedicated to discussing the role of STS in Canada. To be considered for a presentation slot, please submit a 250-400 word abstract [here](#) and indicate if you would like to be considered for a travel bursary. Authors will be notified of acceptance in early March and will be asked to upload a draft workshop paper (2000-5000 words) by mid-April.

Deadline: February 28, 2020

[Call for Proposals: The American Society for Bioethics and Humanities' 22nd Annual Conference](#)

October 15-18, 2020

Baltimore Marriott Waterfront, Baltimore, Maryland, United States

The 22nd ASBH annual conference's theme is *Justice and Flourishing in a Pluralistic World*. The conference takes place at a time when themes that preoccupy the bioethics and health

humanities community are receiving increased national attention. By focusing on justice and flourishing, we invite submissions that interrogate, bolster, and reflect upon those themes and our past, present, and future ways of approaching them. We wonder: What does it mean to seek justice in a world where injustices are manifest? What does it mean to practice tolerance in a pluralistic society, yet also seek truth or certainty in response to moral dilemmas? How should we pursue social justice as educators, scholars, public intellectuals, clinicians, policymakers, and humanists? Should we at all? What is human flourishing and what are the institutions and practices that support it? What role should we have in supporting human flourishing? We invite submissions responsive to questions like these, as well as perennial topics in bioethics and health humanities. We also invite interprofessional and interdisciplinary approaches to these subjects, including empirical bioethics, critical humanities, religious bioethics, activist scholarship, conceptual analysis, education theory, economic analysis, policymaking, and traditional methods in bioethics and health humanities.

Proposals can be submitted for one presentation format only. Allowable presentation formats include pre-conference workshops (3.5 hours), workshops (75 minutes), performances or exhibition (75 minutes, including a minimum of 15 minutes for audience interaction), panel presentations (4 presenters, 75 minutes), debates (75 minutes), paper presentation (15 minutes), flash presentation (75 minutes). To submit a proposal, [click here](#). If you have any questions, contact the ASBH office at info@asbh.org or 847-375-4745.

Deadline: March 2, 2020, 11:59 pm Pacific Time

[Call for Submissions: The European Association for the Study of Science and Technology \(EASST\) and the Society for Social Studies of Science \(4S\) Joint Conference](#)

August 18-21, 2020

Prague, Czech Republic

The theme of the conference is ***Locating and Timing Matters: Significance and agency of STS in emerging worlds***. How has the world changed since 2016 when EASST and 4S met in Barcelona? Since then, efforts to frame “alternative” approaches and futures appear to have been co-opted by powerful actors. Big Data has been fiercely replacing former identities with digital identities for humans, animals and artefacts. Geopolitical and epistemic centres have further multiplied. The global temperature of the planet continues to increase, as do global emissions of CO₂. Wildlife biodiversity is decreasing, while the first CRISPR-Cas engineered babies with altered germlines were born. Modern nation-states have become more unstable even as we see the tentative emergence of new collectives and solidarities. The #metoo campaign has sparked a new wave of articulations of and conflict over gender power asymmetries contributing energy to other ongoing efforts against asymmetric differentiations and exclusions in and beyond academic contexts. We invite STS scholars to examine such spiralling changes that generate these feelings of urgency and powerlessness in ways that make our research relevant to wider academic and non-academic publics. For the meeting in Prague, we especially welcome inquiries into longer term continuities and discontinuities and material legacies of modernity—both desired and undesirable—that have been built into our sociotechnical infrastructures and ways of living. We want to pay special attention to the ways in

which geopolitical, economic and epistemic globalization is localized and distributed over Planet Earth. What are the means and ends of STS in different places? What does it take to intervene and be relevant here and there? Whom do we want to speak and act with? Who wants to speak and act with us? We encourage STS researchers to ask reflexive questions with regard to our own existing and potential practical contributions to these ongoing developments. We welcome experiments in conference formats. Apart from regular paper sessions, we also invite submission of walking seminars, performances and participatory formats of knowledge making and exchange. We plan to collaborate with local artists as unruly participant witnesses and agents of intervention into the conference. To submit a proposal, [click here](#).

Deadline: February 29, 2020.

[Call for Registration: The 4th International Conference on Science Advice to Governments](#)

September 15-17, 2020

Palais des Congrès, Montréal, Québec, Canada

The [International Network for Government Science Advice](#) (INGSA) is hosting the 4th International Conference on Science Advice to Governments, along with Rémi Quirion, Chief Scientist of Quebec, and Mona Nemer, Chief Science Advisor of Canada. More than 600 people from around the world will attend this international conference, which will bring together political representatives, diplomats and government science advisors to promote the role of scientific expertise and evidence in informing policy decisions in an increasingly complex world.

The theme of INGSA 2020 is ***Evidence in context: expanding the dialogue***. The conference will examine the complex interactions between scientists, public policy and diplomatic relations at local, national and international levels. INGSA 2020 will be an opportunity to continue discussions on the United Nations sustainable development goals, the role of cities and municipalities in the appropriation and implementation of evidence and research, the importance of open science and access to data, and finally, the issues raised by disruptive technologies, whether in the digital realm or artificial intelligence. Political and government circles, academics, community leaders and NGO and private sector representatives are invited to take part in INGSA 2020. Click [here](#) to preregister for the conference.

INGSA 2020 will also host a 1-day academic conference. A call for abstracts will be launched during the winter of 2020.

[Appel de candidatures: Bourse de recherche postdoctorale ou d'études supérieures](#)

Unité de recherche en éthique pragmatique de la santé,

Institut de recherches cliniques de Montréal

Montréal, QC, Canada

L'Unité de recherche en éthique pragmatique de la santé est le seul groupe de recherche au monde qui tente explicitement de puiser dans le pragmatisme philosophique pour développer les aspects théoriques, méthodologiques et pratiques d'une éthique de la santé. L'Unité est

présentement à la recherche d'un(e) stagiaire postdoctoral(e) ou d'étudiants aux cycles supérieurs souhaitant contribuer au développement d'une éthique pragmatique. L'étudiant ou les étudiants prendront part au développement de nouvelles théories et méthodologies au cœur de notre programme de recherche ou travaillera sur l'un des nombreux projets plus appliqués mobilisant des approches pragmatiques. Ce poste est d'une durée de 12 mois avec possibilité de renouvellement. Les candidats ou candidates ayant une expertise autre que celle de la bioéthique, mais tout de même connexe (par ex. : sciences de l'implémentation, recherche-action, psychologie, travail social, philosophie) sont aussi invités à soumettre leur candidature. Pour plus d'informations, cliquez [ici](#).

Date limite: Le poste demeure ouvert jusqu'à ce qu'il soit comblé.

Date de début du poste: Dès février 2020.

[Call for Applications: Research Faculty in Bioethics \(Instructor, Assistant or Associate Professor\)](#)

**Center for Bioethics at Harvard Medical School,
Mongan Institute in the Department of Medicine at Massachusetts General Hospital
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. 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.

Deadline: April 1, 2020, although the search will remain open until a successful candidate is found.

[Call for Applications: Visiting Scholars in Health Humanities](#)

**Center for Health Humanities, Massachusetts College of Pharmacy and Health Sciences
Boston, Massachusetts, United States**

The Center for Health Humanities at the Massachusetts College of Pharmacy and Health Sciences invites applications from scholars working in health humanities (broadly understood) interested in spending one to five weeks in residence at their Boston campus. The Center is planning to select at least two Visiting Scholars for the Spring 2020 semester and more for the following academic year. Timing for visits is flexible, but the majority of the period should

overlap with the Spring 2020 semester, or with the Fall or Spring semesters in later years. Visiting scholars will receive a stipend of \$1,000 per week. They will have office space, internet and printer access, and access to library resources. Visiting scholars will be expected to spend time working on the MCPHS campus in Boston during their time in residence. They will give at least one public lecture. They will also contribute to the work of the Center in informal ways, such as classroom visits, or work in progress sessions. These positions are open to both junior and senior scholars (with or without institutional affiliation). Applicants should have a record of achievement in a humanities, social science, or creative discipline appropriate to their career stage. Independent scholars and artists may also apply. Doctoral candidates in the late stages of completing dissertations will be considered in exceptional circumstances. Applicants should have a project in progress or in development that addresses one or more aspects of health, illness, or medicine, or education in the health professions, from a humanistic, humanities, or arts perspective. The Center is encouraging applications from international applicants and those whose work connects with the interests of its Health Humanities faculty members.

The online application must include: a letter of interest explaining how you could contribute to the work of the Center; preferred dates for your intended visit; any alternative dates when a visit would be possible; a one-page description of the project you propose to work on during the period as Visiting Scholar; a CV; a relevant work sample; and the names and e-mail addresses of two colleagues that could answer questions about your work. Further information is available [here](#) or through the Center Director Dien Ho at dien.ho@mcphs.edu.

Deadline: For Fall semester residencies, applications will be accepted from April 15th to June 15th 2020. However, funding might be available for applicants on a rolling basis after the deadlines.

Literature

Interdisciplinary Foundations of Health Ethics

[On the ethics of AI ethics.](#)

Schuklenk U. *Bioethics*. 2020 Feb;34(2):146-147.

[Investigating assumptions of vulnerability: A case study of the exclusion of psychiatric inpatients as participants in genetic research in low- and middle-income contexts.](#)

Palk AC, Bitta M, Kamaara E, Stein DJ, Singh I. *Dev World Bioeth*. 2020 Jan. [Epub ahead of print]

[Public health research, practice, and ethics for justice-involved persons in the big data era.](#)

Rosen DL, Buchbinder M, Juengst E, Rennie S. *Am J Public Health*. 2020 Jan;110(S1):S37-S38.

[Moral limits of brain organoid research.](#)

Koplin JJ, Savulescu J. *J Law Med Ethics*. 2019 Dec;47(4):760-767.

[Determination of death by neurologic criteria in the United States: The case for revising the Uniform Determination of Death Act.](#)

Lewis A, Bonnie RJ, Pope T, Epstein LG, Greer DM, Kirschen MP, Rubin M, Russell JA. *J Law Med Ethics*. 2019 Dec;47(4_suppl):9-24.

Methodologies and Practices in Health Ethics

[An ethical framework to manage patient requests for medical marijuana.](#)

Redinger M, Fledderman N, Crutchfield P. *J Am Board Fam Med*. 2020 Jan-Feb;33(1):147-151.

[How research ethics boards should monitor clinical research.](#)

Apau Bediako R, Kaposy C. *Account Res*. 2020 Jan;27(1):49-56.

[Opportunities to improve shared decision making in dialysis decisions for older adults with life-limiting kidney disease: A pilot study.](#)

Zimmermann CJ, Jhagroo RA, Wakeen M, Schueller K, Zelenski A, Tucholka JL, Fox DA, Baggett ND, Buffington A, Campbell TC, Johnson SK, Schwarze ML. *J Palliat Med*. 2020 Jan 13. [Epub ahead of print]

[Oversight of right-to-try and expanded access requests for off-trial access to investigational drugs.](#)

Chapman CR, Eckman J, Bateman-House AS. *Ethics Hum Res*. 2020 Jan;42(1):2-13.

[Optimizing community bioethics dialogues: Reflections on enhancing bi-directional engagement on health care concerns.](#)

Crowder JW, Determeyer PL. *Narrat Inq Bioeth*. 2019;9(3):259-273.

News and Social Media

[Aide médicale à mourir et santé mentale: Québec recule](#)

Lacoursière A. *La Presse*. January 27, 2020.

[To restore humanity in health care, address clinician burnout](#)

Rushton CH. *The Hastings Center*. January 16, 2020.

[Made health resolutions for 2020? You might not be living a free life](#)

Reuter SZ. *The Conversation*. December 20, 2019.

[The invention of "ethical AI": How Big Tech manipulates academia to avoid regulation](#)

Ochigame R. *The Intercept*. December 20, 2019.

[On fabrication des patients psychiatriques à la chaîne](#)

Renard H. *Le vif*. December 10, 2019.

Other resources

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



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